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ABSTRACT

This report contains the findings and recommendations of a review of the residential services system for South Dakota adults with developmental disabilities, based on site visits, interviews, and an analysis of documents and materials. The policy analysis report examines how South Dakota could implement a "person-centered," "individualized," or "housing/support" approach to community living for adults. An introductory section describes the current design of South Dakota residential services, examining its continuum-based model of services, private vendor system, supporting structures at the state level, and residential program models. The next section offers recommendations for strengthening the current system of community services, focusing on seven issues: regional control, accountability, and accessibility; supporting people with severe disabilities in the community; funding for community services; planning and communication; staff roles, training, and recruitment; quality of services and safety; and community integration. The final section analyzes recommendations for incorporating a more "individualized" approach to support. It deals with the issues of separation of housing and support services; individualized and flexible supports; housing and home ownership; individual assessment, planning, and funding; and consumer-directedness of services/housing. Appendices contain literature excerpts and other supporting documents on supporting adults in the community, information on the methodology for the policy analysis, and a copy of "New Directions in Housing for People with Severe Disabilities: A Collection of Resource Materials" prepared by Susan O'Connor and Julie Ann Racino. (28 references) (JDD)

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Center on Human Policy

MOVING INTO THE 1990s: A POLICY ANALYSIS OF COMMUNITY LIVING FOR ADULTS WITH DEVELOPMENTAL DISABILITIES IN SOUTH DAKOTA

EC 300 644

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MOVING INTO THE 1990s: A POLICY ANALYSIS OF COMMUNITY LIVING FOR ADULTS WITH DEVELOPMENTAL DISABILITIES IN SOUTH DAKOTA

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INTRODUCTION

This report contains the findings and recommendations of a review of the system of residential services for adults with developmental disabilities in South Dakota. The primary purpose of the report is to assist the South Dakota Division of Developmental Disabilities to improve the integration and participation of adults with developmental disabilities in communities in South Dakota.

This policy analysis was primarily directed toward examining how South Dakota could implement an emerging approach to community living for adults called a "person-centered," "individualized," or "housing/support" approach. Based on the right of an adult to live in the community with appropriate supports, its primary service features include: the separation of housing and support services; the promotion of integrated housing and home ownership; individualized and flexible supports; individual assessment, planning, and funding; and consumer-directed services and housing. Background information on this approach is contained in Appendix I.

This report addresses one of the recommendations of an excellent, detailed report by the National Association of State Mental Retardation Program Directors (NASMRPD) titled "An Assessment of Services to South Dakota's Citizens with Developmental Disabilities" (Smith & Gettings, July 1988, pp. 138-139). Specifically, this recommendation states:

> Recommendation IV: South Dakotans should examine the experiences of other states that have used supported living arrangements as a means of meeting the diverse residential needs of persons with developmental disabilities and determine the steps necessary to implement such programs in South Dakota.

This analysis draws upon our research and training in other states, including North Dakota and Colorado, which are mentioned in the NASMRPD report. A copy of the relevant pages from this report are in Appendix II.

Based on an analysis of the data, this report is divided into two primary sections:

First, what are recommendations for strengthening the current system of community services for adults with developmental disabilities? In other words, what are steps that can be taken to improve the quality of life of people with developmental disabilities under the traditional design of community services? This section also specifies the essential changes necessary as the foundation for an "individualized" approach to supporting adults.

Second, what are recommendations for incorporating a more "individualized" approach to supporting adults with developmental disabilities in South Dakota? In other words, what are steps that South Dakota can take on a short-term and a long-term basis to implement an "individualized" or "housing/support" approach in the state?

This policy analysis was conducted through a technical assistance and training agreement with the South Dakota Office of Developmental Disabilities. The review is based on site visits, interviews, and an analysis of documents and materials conducted between October 1988 and August 1989. Appendix III summarizes the methodology on which this analysis is based.

CURRENT DESIGN OF SOUTH DAKOTA RESIDENTIAL SERVICES SYSTEM

Continuum-Based Model of Services

As in all the states, the design of the residential services system in South Dakota is primarily based on the principle of the least restrictive environment (LRE), together

with its implementation as a continuum. In other words, people with the most severe disabilities generally are served in the most restrictive settings (i.e., the institutions) and people with the mildest disabilities are served at the least restrictive end (i.e., independent living). As people acquire more skills, they are expected to "graduate" or "transition" to more independent settings (Taylor, Racino, Knoll & Lutfiyya, 1987). While the continuum was important in the early development of community services systems, there are a number of pitfalls with the continuing use of the continuum concept and the LRE principle to guide the design of service systems (Taylor, 1988). These include:

* **People with severe disabilities get relegated to the "most restrictive" end of the continuum.**

  People with severe disabilities who enter the service system in South Dakota are often served in institutional settings. In addition, many service providers assume that people with developmental disabilities must move from Custer to Redfield (the two public institutions) before being considered for community placement.

* **The most restrictive placements, such as institutions, are not necessary.**

  Despite research to the contrary, current legislation in South Dakota states that Redfield "shall be maintained" and community services "may be established" indicating a strong institutional bias still existing in the state.

* **The continuum implies people need to leave their homes every time they acquire new skills.**

  Physical movement from site-to-site by people with developmental disabilities is generally viewed as positive and seen as a sign of growth in South Dakota. Even community facilities of the same type (e.g., supervised apartments) may be viewed as succeeding steps on the continuum, with an expectation that people physically

move to a new site for minor changes in staffing, space or integration. Often there is limited awareness of the disruptive effect this may have on a person's relationships and community connections.

* **The most restrictive placements do not prepare people for the least restrictive placements.**

The "readiness" model which has fallen into widespread disrepute is still viewed by many people in South Dakota as one of the greatest strengths of the current residential services system. In South Dakota, teachers may not be receiving the training they need in educating children with severe disabilities. Thus, the adult service system is not being adequately "pushed" to change its services to reflect the limitations of a "readiness" model for people with severe disabilities. These limitations are well documented in the field of education research.

* **The continuum concept confuses people's rights with the intensity of their service needs.**

There is still an emphasis on people needing to "earn" the right to live in a typical home, although one provider said there could be "exceptions" to this rule. Having a need for more intensive supports need not and should not be equated with an abridgement of one's rights. In South Dakota, people with severe disabilities often must choose between a home in the community or the appropriate supports. This is an unfair and unnecessary choice.

* **The continuum directs attention to physical settings rather than to the services and supports people need to be integrated in the community.**

The most recent example in South Dakota is the statewide effort to develop supervised apartment buildings to "fill a hole in the system." Instead of examining the intensity and type of supports necessary, the focus has been on the financing

and developing of supervised apartment buildings for people with developmental disabilities.

Today, we know that all people with developmental disabilities, including those with severe developmental, behavioral, and health impairments, can live successfully in the community, if appropriately supported. Evidence and experience indicates that life in the community is better than life in institutions in terms of relationships, individual development, family contact, frequency and diversity of relationships, and leisure, recreational and spiritual resources (Leadership Institute, 1988). Children can be supported to live with families and adults can be supported to live in typical homes. The intent of this report is to examine the barriers that must be addressed in South Dakota to enable this to occur. Since the issues in supporting children and adults are distinctly different, the remainder of this report will discuss only the implementation of this approach for adults. A similar effort should be undertaken regarding the steps necessary to insure that children can be supported in families.

Compared to most states, South Dakota's residential service system is even more firmly rooted in a continuum-based design of services. In some ways, this can be perceived as a positive aspect of the South Dakota system. It indicates that the state made efforts to develop a range of different residential options for people with disabilities. Also when a need was recognized (e.g., for alternatives to the community residential facilities), the state Division of Developmental Disabilities (DDD) and the private Adjustment Training Centers (ATCs) tried to address this need (through the development of supervised apartments buildings). However, this report proposes other ways of recognizing and meeting the needs of people with developmental disabilities that can better promote their living and participating in the community. Despite the state's

small size, changing from a continuum approach may be even more difficult in South Dakota than in some states because of its firm commitment to this model of service design.

Private Vendor System

The primary structures for the delivery of community services for adults on the local level are the seventeen (17) Adjustment Training Centers located throughout the state. Each operates as a private, non-profit organization providing a range of different residential and day services to people with developmental disabilities. According to recent amendments to South Dakota public law 27-A-1-2, an "adjustment training center" is defined as

> any private nonprofit organization which receives financial assistance from the state or its political subdivisions and which is established or organized for the purpose of providing intensive training, closely supervised work situations or day activity services and which meets the currently adopted rules of the department of human services for adjustment training centers.

Generally, the ATCs tend to serve people from the geographical area around the ATC, although several "specialize" in serving certain populations from across the state.

In comparing and contrasting themselves to other ATCs in the state, the ATC directors generally commented on one or more of the following dimensions: the nature of the local community, the size of the ATC, particular characteristics of the people served, and progressive efforts in service areas.

Size. The ATCs vary tremendously in terms of size. There are two major and apparently expanding ATCs in the state, Sioux Vocational Services located East River

FIGURE 1

PRIMARY DIFFERENTIATING CHARACTERISTICS OF THE ATCs

Size

Nature of the Local Community

Characteristics of the People Served

Progressive Nature

and Black Hills Workshop and Training Center located West River. On the dimension of residential services (including followalong) for adults, these two providers accounted for 15% (156 adults) and 20% (199 adults) respectively of all such services in the state. In contrast, the smallest number of adults served by an ATC during the same period was OAHE at 12 (1.1%) and Southern Hills at 14 (1.3%). For comparison purposes, the mean number of adults served by all the ATCs was 60 and the median number 40 (Data source Form DD-720; 7/1/87-6/30/88).

Their generally small sizes are one of the strengths of the ATCs. Small organizations are more able to support people individually and flexibly. Most of the private agencies in our national study of promising practices in community living supported 100 or fewer people in the community. Even the larger ATCs have some capacity to have a relatively flat administrative structure that can minimize the distance between people with disabilities and administrators in the organization.

Nature of the local community. Several ATCs specifically mentioned the importance of their very rural nature and location in towns with small populations. Three of the ATCs working with Native Americans also said this was a significant feature affecting the nature of their ATC.

Characteristics of the people served. If an ATC "specialized" in serving a certain population group, this was usually mentioned early in the interviews. These included people with physical needs (United Cerebral Palsy), people with challenging behaviors (Yankton) and people who are both deaf and blind (ATCO).

Progressive efforts in services. Particularly for the larger ATCs, "being in the forefront" in areas such as work opportunities, and philosophy (e.g., choices, rights) seems very important as a way of viewing their roles. These ATCs are conscious about how they compare to other ATCs in South Dakota and to other progressive services in the country.

While each of the ATCs is unique, these four characteristics are important in understanding how the individual ATCs perceive themselves. These characteristics also provide information on important areas to examine in future directions in the state. As private entities, the ATCs appropriately have no mandated responsibilities typical of public or quasi-public regional structures. For example, catchment areas are not designated, entrance and exit criteria vary between the ATCs, public input is not mandated, and the organizations determine their own goals. While this is a reasonable approach to the private sector, the implications for parents and people with disabilities will be discussed later in this report.

The ATCs are, however, governed by the regulations of the Department of Human Services and are heavily reliant on funding through DDD. Specifically, the Secretary of Human Services does have the authority to develop "reasonable and necessary rules establishing standards for adjustment training centers" in the following areas: "staff requirements; administration, audit and record keeping services provided;

client rights and safety; facility fire safety and sanitation requirements; and such other standards that are necessary for federal financial participation." (27-B-2-11)

While the ATC structure will be discussed in depth later in this report, several issues are important to note here. First, there is tension between the ATCs and the state Division of Developmental Disabilities (DDD) regarding the role and autonomy of the ATCs. Part of this tension is inherent in the different roles of these organizations. However, part of the problem seems to be related to an emerging structural problem in the design of supporting structures[1] in the state.

Second, several of the smaller ATCs are concerned about their own survival, especially as the larger ATCs expand. Generally, however, the ATCs are supportive of each other and the ATC directors see their support for one another as an important strength in the state. As in many states, their association has increasingly lobbied for the private sector development of community services.

Third, at least one special education services cooperative (which provides children's services) is seeking to develop residential services for adults that will compete with services offered by the ATCs. While this will not be discussed in depth in this report, such approval would exacerbate problems already developing between the cooperatives and the ATCs. Part of these tensions is related to differences in role, but also point to the previously mentioned structural problem which will be discussed under Issue 1.

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[1]Supporting structures - In designing a system from the individual up, these are organizational structures at the agency, regional and state levels whose main functions should be to support the individual/family.

Finally, the ATC structure has been very important in the development of the service delivery system in South Dakota. It is generally an unquestioned method of service organization and delivery. While the structure was critical to building the stability of the community service system to-date, changing issues may today require a re-examination of its usefulness in addressing the problems now facing parents, people with disabilities, providers and administrators. Structures that are useful at one point in the development of a service system may at another time become a barrier to further changes.

Supporting Structures at the State Level

The state Division of Developmental Disabilities (DDD), previously under the Department of Social Services, is charged with the primary responsibility of delivering community-based services to adults with developmental disabilities in the state. It has legislative authority for the seventeen ATCs and limited responsibility for services for children. Three program coordinators (from a total of seven central office staff) serve as liaisons and program monitors with designated private agencies.

Several major changes have recently occurred and had an impact on the structures for delivering services for people with developmental disabilities in the South Dakota. These are still in the process of implementation.

First, a constitutional amendment eliminated the Board of Charities and Corrections, an independent state agency previously responsible for the administration of the two large public institutions for people with developmental disabilities. Second, the Office of Developmental Disabilities and Mental Health (ODDMH) was moved from the Department of Social Services (DSS) into a newly created Department of Human

Services (DHS), which also includes drug and alcohol abuse, and vocational rehabilitation. Third, institutional and community services are now located in the same Department of Human Services as opposed to under separate authorities.

In general, we believe these are important steps toward developing a unified service system for people with developmental disabilities in South Dakota. We do, however, concur with the concerns expressed in the NASMRPD report that creation of the new department must be accompanied by the necessary administrative resources DDD will need to fulfill its responsibilities. The DDD is particularly stressed at this time since its director continues to also serve as director of the Division of Mental Health until a new DMH director is hired.

The NASMRPD report provides an overview of the roles and responsibilities of all state agencies supporting people with developmental disabilities in South Dakota. The reader is referred to that report for a description of the roles and responsibilities of other state agencies serving adults with developmental disabilities, particularly the Department of Vocational Rehabilitation (DVR); the Department of Health (DOH); the Department of Education and Cultural Affairs (DECA); other units of the Department of Social Services (DSS), including the Office of Medical Services, the Office of Economic Assistance, the Office of Adult Services and Aging; and the Indian Health Services.

Residential Program Models

There are a number of different ways to describe the residential program models used in South Dakota today. The system is in many ways a unique cross between a

traditional continuum-based system of residential facilities and the emerging approach to individualized services. This will be described in more detail later in the report.

The first way to examine the program models is from the viewpoint of the facilities or places where adults with developmental disabilities live and obtain services. As in most service systems, the South Dakota system is primarily facility-based with the program revolving around the facility instead of the individual. These facility categories include:

(1) **State-operated Institutional Services**. South Dakota has two publicly operated institutions for people with developmental disabilities. As of April 1989, 105 people resided at Custer and 319 people at Redfield. Both institutions are funded as Intermediate Care Facilities.

(2) **Crippled Children's School and Hospital**. This is a privately operated institution certified as a specialty hospital through the Department of Health. It serves no adults over the age of 21, but may refer children to the public institutions or to the ATCs.

(3) **Private Nursing Homes**. In April 1989, over 142 people with developmental disabilities who were classified as in need of community placement were residing in approximately 135 private nursing homes licensed by the Department of Health. South Dakota has developed an alternative disposition plan (ADP) and is in the process of implementing this plan for these individuals.

(4) **Intermediate Care Facilities for the Mentally Retarded-15**. These are community residential facilities for not more than 15 people (and generally no fewer than 9). They are certified by the Division of Developmental Disabilities, the Department of Social Services (Office of Medical Services) and the Department of

Health as capable of providing Title XIX health-related services to people with developmental disabilities. As of June 30, 1989, 158 adults resided in these ICF-MRs.

(5) **Community Residential Facilities.** In most states, these would be called group homes. Sixteen (16) or fewer people live in these facilities which are certified by DDD to provide "residential services, training in skills needed for independent living, recreational activities, and basic supervision of developmentally disabled people." They are funded through the Title XIX Medicaid waiver, Title XX, Vocational Rehabilitation 110, Special Education, SSI and/or private pay. As of June 30, 1989, 441 adults resided in these facilities.

(6) **Supervised Apartments (Community Residential Facilities).** These are apartments for four (4) or fewer people with developmental disabilities "with separate bathing and cooking facilities in each unit." By administrative rule, up to sixteen (16) people can reside in one building exclusively serving people with developmental disabilities and sites must be at least 300 yards apart. Twenty-four hour on-site staff is required within the complex. Funding and certification are the same as for the CRFs. As of June 30, 1989, 194 adults resided in supervised apartments in the state.

Most supervised apartments are located in apartment buildings constructed by the ATCs exclusively for people with developmental disabilities. Currently, at least five (5) new apartment buildings of this nature are being developed across the state. The supervised apartment buildings are viewed by most ATC directors as one of the most desired options for future residential services development.

(7) **Monitored Apartments.** These are defined in the standards as "an uncertified apartment with self-contained bathing and cooking facilities for up to 4 developmentally disabled persons." Generally, a person is considered to live in a "monitored apartment"

if the service agency leases the apartment and/or if the person with a disability leases the apartment, but receives training from the service agency. However, the definition of a monitored apartment seems to vary in the state.

By administrative rule, staff must be available seven days a week and be located no more than fifteen minutes away from the site. People in monitored apartments typically receive either followalong or community living training (defined later in this section). Monitored apartments must meet local safety codes and be approved by the interdisciplinary team (IDT) whose decisions can be challenged by the state DDD. Monitored apartments are often located in clusters or in immediate proximity to other residential sites (e.g., attached to a group home). As of June 30, 1989, approximately 111 adults resided in monitored apartments.

(8) **Adult Foster Care**. Adult foster care is defined as "a family residence where an aged, blind, physically disabled, developmentally disabled, or socially-emotionally disabled adult can obtain personal care, health supervision services, and household services in a family atmosphere." DSS's Office of Adult Services and Aging is responsible on the local level for matching, selecting, training, and supervising adults with developmental disabilities in adult foster care. Licensing is done by Child Protection. As of June 30, 1989, at least 80 adults with developmental disabilities resided in adult foster care homes.

(9) **Family Home**. Through standards, this is defined as "an uncertified living arrangement in which a developmentally disabled client lives with his parents, other relatives or legal guardians." As of June 30, 1989, there were 171 adults with developmental disabilities who were living at home, but receiving services through an

ATC. Generally, these services were limited in practice to involvement in a day program and/or transportation to/from the day program.

(10) **Independent Apartments.** These are apartments generally shared by one or two people where followalong is provided and/or where people who participate in day program services from an ATC live. These are people's own places and are appropriately not addressed in administrative rules.

Table 1 gives an overview of the residential models in South Dakota. In reviewing the table, it is important to note the following:

1) 72% of the adults known to the service system receive services in the community with approximately 28% remaining in the public institutions or private nursing homes.

2) Approximately 34% of the adults (or 50% of those receiving services from the ATCs) are in congregate living arrangements, generally in homes of 9-15 people.

3) Of the approximately 23% of the people in apartment settings, almost half are in supervised apartments, primarily located in segregated apartment buildings. People residing in monitored apartments may also be located in primarily disability-segregated locations.

4) The approximately 6% of the people in monitored apartments generally receive minimal support and the approximately 6% in independent apartments may receive little, if any service, other than the day program.

5) The approximately 14% of the people in foster care or in family homes generally receive only day program services from the ATCs.

TABLE 1
USE OF RESIDENTIAL MODELS IN SOUTH DAKOTA

RESIDENTIAL MODEL	TOTAL PEOPLE SERVED*	TOTAL ADULTS (AGE +21) SERVED*	%ADULTS SERVED IN THIS MODEL
1. State Institutions			
Custer	104	84	20.7%
Redfield	307	282	
2. Crippled Children's Hospital	92	0	0.0%
3. Nursing Homes	142	140	7.9%
4. Small ICF/MR <15 (Community Residential Facilities)	183	158	8.9%
5. Community Residential Facilities (Group Homes)	500	441	24.9%
6. Supervised Apartments (Community Residential Facilities)	208	194	10.9%
7. Monitoring Apartments	114	111	6.3%
8. Foster Care	100	80	4.5%
9. Family Home	206	171	9.7%
10. Independent Apartment	110	108	6.2%
TOTAL	2,066	1,769	100.0%

*All data as of June 30, 1989, except for Custer (6/30/88) and nursing homes (4/89).

As described below, most of the residential services in South Dakota can be called "facility-based services." Typically, facility-based services have the characteristics listed in Figure 2.

FIGURE 2

CHARACTERISTICS OF FACILITY-BASED SERVICES

Agency owned or rented facilities
Licensed or certified facilities
Agency staffed
Staffing ratios based on groups not individuals
Linkage of housing and support services
Core funding tied to facility
Weak relationship between funding and individual planning
Facility classification based on supervision needs

Agency owned or rented facility. Since providers own or rent the residential settings, they ultimately control who lives there. As O'Brien and Lyle (1986) point out, under this arrangement, "the person is a guest in someone else's home."

This is a particularly important issue in South Dakota because providers own buildings (e.g., supervised apartment buildings) that often in other states would be owned by another landlord. Also South Dakota has recently relied heavily on new construction and many of its buildings are under 30-50 year mortgages from Housing and Urban Development (HUD) and the Farmers Home Administration (FmHA).

Licensed or certified facilities. When agencies own or lease and operate facilities, licensing or certification are appropriate. However, by its nature, licensing

tends to limit people's choices and places decision-making in the hands of people who do not live there.

In South Dakota, as in most places, facilities are licensed or certified, with the exceptions of monitored apartments (which may or may not be leased by the agency), independent apartments and family homes. People's own homes and apartments should not be licensed. However, monitored apartments leased by agencies should generally be certified.

Agency staffed. Staff are hired, paid, and supervised by the agency. Staff are employed by and accountable to the agency, not the people receiving services. The staff's relationship with the people is defined by conditions of employment set between the agency and the staff.

The ATCs generally employ only agency staff and did not seem to involve the people with disabilities in the staff selection process. One agency, however, did mention using a stipend approach with one neighbor (Huron) and another investigated paying a stipend to a person with a disability, but encountered a barrier with their insurance company (ECCO). In addition, several ATCs noted that if people with disabilities were to have staff accountable to them, they should be served by the independent living centers or home health care agencies. These ATCs defined their role as the provision of residential facilities.

Staffing ratios based on the group not on individuals. Staffing ratios and levels of supervision are based on the group and not on the individuals. To the extent that an individual has more or less supervision needs, s/he may not "fit into the program."

As will be discussed later, the staffing ratios in the community residential facilities greatly limit who can be served within these facilities. The ratios are generally

inadequate to support people with very severe disabilities. Unlike our visits to other states, there was no evidence of overstaffing within any of the places we visited. Staffing is based on facility not individual needs of people. There is flexibility to move staff and resources between residential programs on a short term basis.

Linkage of housing and support services. Generally, people must live in the providers' facility to receive intensive support services.

South Dakota already has precedents for providing services to people in their own apartments/homes. Except for the ICF-MRs, with minor modifications, a separation between housing and support services could be further extended. South Dakota providers, however, view their major role as providing facilities for training. A strong distinction (that goes beyond funding requirements) is made between providing supports and training.

Core funding tied to the facility. The funding is based on the facility and not the individual. Funding would not follow the individual if s/he moved to a new home.

South Dakota has defined its community living training, followalong and home and community-based Medicaid waiver services in a way that could make it relatively easy to modify the funding (except for the ICF-MRs) to support people in typical homes. The major problem South Dakota faces is its current financial commitments to existing buildings.

Weak relationship between funding and individual planning. The rate-setting and individual planning processes proceed relatively independently.

This is a particular problem in South Dakota with major disincentives existing for providers to serve people with severe disabilities. The processes are almost

totally independent of each other and current rates are inadequate to support people with the most severe disabilities in the community.

Facility classification based on supervision needs. Facilities are primarily classified as providing either 24-hour supervision or less than 24-hour supervision.

Compared to many states, this is not as great a problem in South Dakota. Many of the people in the community residential facilities are relatively independent and do not, in fact, have 24-hour supervision in the strict sense of the word. For example, they will come and go from the house without staff. There also is precedent for having people with different supervision needs in the same facility. All of these issues will be discussed in more depth in the second section of the report on non-facility-based approaches to supporting people in the community.

Another way to examine the residential program models used in South Dakota is to look at the categories of community residential services funded in the state. Under the administration of DDD, these include:

(1) **Community living training** (CLT) is a "planned and systematic program to develop skills in food preparation, care and purchase of clothing, self-care skills, proper health care, housekeeping, time and money concepts, peer relationships and other skills as appropriate." CLT is funded at either full or half time. Full-time CLT requires training at least 4 hours a day, 5 days a week, with the capacity to provide services everyday of the week. Half-time CLT is on the average between 2 and 4 hours/day, 5 days per week.

(2) **Followalong/outreach** provides casemanagement, followalong and outreach services to people who have minimal support needs. It is not a training program,

requires no individual habilitation plan, is monitored by the DDD on contract compliance, and pays a standard rate per client per month.

(3) **Home and community-based services** provides habilitation and training, casemanagement, and other selected specialized services that might be necessary to assist the person to reside in the community. The waiver funds both daytime and residential services, but currently does not include prevocational services, home modifications or supported employment as fundable categories.

(4) **Community intermediate care facilities** are Medicaid funded group living facilities for fewer than sixteen (16) people with developmental disabilities.

Table 2 contains information on the number of adults with developmental disabilities in residential programs funded through community living training, followalong, home and community-based services and small intermediate care facilities. In reading the table, a few items are particularly noteworthy:

1) Only 17% of the adults are funded through the restrictive ICF-MR funding source with 83% supported through more flexible funding sources.

2) 59% of the people are funded through Medicaid (including the state match portion).

3) While Medicaid waiver funds are used throughout the state, only seven of the ATCs serve people in Intermediate Care Facilities (ICF-MRs).

This view of the residential service system separates the types of services from the location of those services, except in the Intermediate Care Facilities where by federal definition the location and service are combined. A service system based on this view can look very different than the previously described residential program models that currently exist in South Dakota. This will be discussed in more depth in the succeeding sections.

TABLE 2
RESIDENTIAL AND FOLLOWALONG PROGRAMS
AVERAGE DAILY CASELOAD
7/1/87 - 6/30/88

SERVICE PROVIDING AGENCY (ADULTS ONLY)	ICF	HCBS	CLT	FOLLOW ALONG	TOTAL
1. ATCO Enterprises, Inc.	----	49	15	17	81
2. Aberdeen Adjustment Training Center	----	44	10	19	73
3. Black Hills Workshop and Training Center	38	45	52	65	200
4. Brookings Area Adjustment Services	11	33	14	17	75
5. Chamberlain Adjustment Training Center	----	14	12	---	26
6. ECCO, Inc.	12	18	2	9	41
7. Huron Area Adjustment Training Center	19	23	10	17	69
8. LIVE Center, Inc.	----	16	12	1	29
9. Mitchell Area Adjustment Training Center	11	15	23	10	59
10. Northern Hills Training Center	----	16	6	6	28
11. OAHE, Inc.	----	6	2	5	13
12. Sioux Vocational School	43	78	11	24	156
13. South Central Adjustment Training Center	----	15	6	4	25
14. Southeast South Dakota Activity Center	----	23	11	1	35
15. Southern Hills Developmental Center	----	5	6	3	14
16. United Cerebral Palsy ATC	37	----	---	---	37
17. Yankton Area Adjustment Training Center	----	33	10	14	57
TOTAL	171	433	202	212	1,018

Mean= 60
Median = 41
Data Source: Form DD-720, SD ODD/MH

PART I:
STRENGTHENING THE CURRENT SYSTEM OF COMMUNITY SERVICES

Strengths to Build On

In examining future directions to better support people with developmental disabilities in community living in the state, it is important to start with the strengths that currently exist. There are several strengths that stand out as particularly relevant to the changes discussed in this report. These include:

Building a community system together. Many of the key people currently involved with community services in South Dakota are the same individuals who helped to build the current community system over the past dozen years. While people recognize the system is not perfect, there is an appreciation for the many barriers crossed, the compromises made, and the achievements accomplished in establishing a community service system for over 1,400 people with developmental disabilities.

Stability and experience of key personnel. The consistency in state leadership has been an important factor in building the community service system through the years. Especially in a state where the increase in central office staff has not kept pace with the increasing responsibilities of that office, stable, experienced leadership is key. Also, despite the tensions that exist, generally there is respect for the leadership in the DDD.

Openness to change. All but one of the ATC directors expressed a willingness to consider a more individualized approach to supporting adults in the community with several actively interested in pursuing this approach. The state Division of Developmental Disabilities should also be commended for its efforts to seek information about promising practices in supporting adults and for stressing the importance of involving a wide range of people at looking at these issues.

Flexibility and responsiveness. Compared to many states, the current system of financing, while problematic in many ways, provides some flexibility to the agencies, thus allowing for more local decision-making. In addition, the casemanagement ratios established at the ATCs are very good and the development of "followalong" has increased the responsiveness of the services to people's needs. The ATCs all are concerned with the well-being of people with developmental disabilities.

Selected integration efforts. All of the ATCs and the state DDD express support for some version of normalization and integration as guiding principles for the service system. Several of the ATCs have made conscious efforts to increase the integration of people with disabilities into community life, including helping people to build connections with other community members and participate individually in regular community activities and events. The state DDD has attempted to promote community integration through a variety of mechanisms, such as current regulatory changes decreasing the size of new homes.

ISSUES AND RECOMMENDATIONS

This section of the report will examine issues and recommendations that are critical under the traditional design of residential services and as the foundation for major systemic change to an "individualized" approach to supporting adults in community living.

Issue 1: Regional Control, Accountability and Accessibility

The ATCs are private, non-profit providers which rightfully do not have mandated responsibilities for services to people with developmental disabilities and their

families. On the state level, the Department of Human Services has the primary responsibility to coordinate state planning and to coordinate services for people with developmental disabilities and their families. There is, however, no regional authority in South Dakota for regional planning and individual services coordination for people with developmental disabilities and their families. This affects families and people with disabilities in a number of different ways.

First, **there is no public mechanism on the regional level insuring that parents, people with disabilities and community members can have input into community services and supports for people with developmental disabilities**. Whether and how such input is sought is carried out by the understaffed state DDD or at the discretion of the ATCs.

Second, **there is no single point of entry on a regional level for community services for people with developmental disabilities in the state**. Parents or adults with developmental disabilities who apply for services at the ATC in their geographical area may be referred to another ATC in a different geographical area, to the state DDD, to one of the state institutions, to a private facility such as Crippled Children's Hospital or placed on a waiting list. Except for a few individuals within the service system, there seems to be limited awareness about the detrimental impact on families and friends that could be caused by removing people with disabilities from their home communities. Several parents mentioned that the distance between their home and their child's residence was problematic, but they accepted the distance because there was no other viable option.

Third, **there is no regional authority with a mandate to plan for services for people with developmental disabilities**. First, the ATCs do not have a designated

catchment area. In fact, some ATCs clearly saw their responsibilities as related to the town in which they were located, not a broader regional area. Second, the ATCs are not responsible for planning for the future services and supports that may be necessary for people with disabilities and their families in the region. As one example, ATCs do not have information concerning out-of-region placements. Such information would be necessary to plan supports and services for individuals and to develop the necessary administrative structures and regional capacities to support these individuals in the community.

Fourth, **there is no regional authority with mandated responsibilities to coordinate services for people with developmental disabilities**. The increasing tension with the cooperatives is partially a result of a structure in which local coordination is not a clear responsibility. This will become an ever increasing issue as greater coordination with a wider range of agencies is required in providing more individualized supports.

Fifth, **there is no regional authority whose role is to support people with developmental disabilities in the community**. Most of the ATCs viewed their roles as providing certain residential and vocational programs. If people needed other types of supports (e.g., supports in their own homes, adult foster homes), this was often defined (by the ATCs) as the job of another organization or agency in the state.

This issue is one of primary importance for the future of people with disabilities in South Dakota. While there are a number of possible solutions, the first step must be the recognition of the structural basis for many of these emerging problems and the necessity of developing new structures that can better support people with disabilities and their families in the coming years.

Long-Term Recommendation 1A: The South Dakota Division of Developmental Disabilities should develop a process to examine the establishment of a regional mechanism for individual/systems coordination and regional planning.

According to South Dakota legislation, it appears that the Department of Human Services may establish community services for people with developmental disabilities and that these can be provided through ATCs, other nonpublic facilities or by the Department itself. In addition, the legislation states that the Department of Human Services "may establish and use state, regional, or local boards or councils to assist in the planning and implementation."

Given this authority, there are many options that the Department of Human Services may consider and a few are presented here. This report deals specifically with issues related to adults with developmental disabilities. Decisions regarding structure, however, must also include a review of the current cooperative structure in the state. This is not meant to imply that the current structure has not been a useful or effective one in the past. To the contrary, it has enabled South Dakota to establish a relatively stable system of community services. However, the future holds new challenges and it is time to re-evaluate the changes necessary to move South Dakota forward in the next decade.

The following are presented as options to start people thinking about possible structural changes:

First, some of the ATCs could be given clear, mandated public responsibilities somewhat akin to the quasi-public-private area agency structure developed in New Hampshire. They could then continue to provide services directly and/or contract with other providers for services. In any case, it would be worthwhile for South Dakota to at

least examine the New Hampshire structure. It maintains the flexibility of the current arrangement (and some of those problems), but also would add a greater degree of public responsibility and accountability than exists in the current system. It is important to note, though, that each system is unique and models cannot simply be transferred from one state to another.

Second, the ATCs could remain as private, nonprofit providers and the state could establish regional offices with responsibilities for individual and systems coordination and regional planning. To be effective, these regional structures must be given substantial authority including major roles in funding as well as monitoring, planning and coordination issues. While a positive step, simply adding external casemanagement (sometimes called service coordination) to a largely provider-driven system is not likely to resolve many of the problems of the current system described earlier in this report. With adequate resources, the state DDD should have the capacity to establish and effectively operate such offices.

At this stage in the development of community services in the state, there is a need for greater local responsibility for the welfare of people with developmental disabilities. This recommendation would address a number of emerging issues in the system including those expressed by the ATCs and the state DDD. Even though the recommendation is long-term in nature, short-term decisions made today in South Dakota must take into account the planned future structure in the state. As an initial step, this recommendation is primarily designed to foster discussion of the many complex issues involved in this fundamental change in the service delivery structure in the state.

Issue 2: Supporting People with Severe Disabilities in the Community

This review examined the current capacity of the community service system to support people with severe disabilities in South Dakota, including people currently living in the institutions. There are four major issues discussed in this section: unserved or underserved populations, waiting lists, the role of the institutions, and barriers that must be overcome to support people with severe disabilities in the community.

Unserved or underserved populations. A number of the ATCs reported increased efforts to extend their services to people with greater needs than they served in the past (e.g., people who need assistance in toileting, people with profound mental retardation). This view was supported by parents who saw the capacities of the ATCs grow through the years. Several ATCs also viewed themselves as "specializing" in serving people with particular needs, such as people with physical disabilities (United Cerebral Palsy), people who are both deaf and blind (ATCO), or people with "challenging behaviors" (Yankton). Most ATCs reported that whom they served was mainly dependent on the staffing ratio the person needed. Typically, they could not serve any individual needing more than a one-to-four staffing ratio (due to funding issues) or people who needed injections or tubefeeding (due to policy barriers).

Underserved population groups most commonly mentioned in interviews as needing community services included people involved in both the mental health and mental retardation systems, in the criminal justice system, or who have some kind of "challenging behaviors." There is also growing interest in supports for parents who are mentally retarded, for children transitioning to adult services, for the elderly individuals residing at Redfield, and for people with medical needs. Parents also cited the need for

better training and awareness about disabilities other than mental retardation (e.g., autism, epilepsy).

Waiting lists. As of August 1989, almost all of the ATCs had people waiting for services who could not be served primarily due to financial constraints. The state DDD was in the process of compiling waiting lists and was starting efforts to address many of the issues described in the remainder of this section. While the ATCs are typically aware only of people who have applied for their services, several major problems existed with current waiting lists:

First, people from the institutions were often not included on the waiting lists, partially because they were viewed as already being served in the institutions. Also since people in the community were viewed as "without services," the ATCs placed lower priority on the need for community services for people in the institutions.

Second, the same individual could appear on many different waiting lists since there was no fixed point of responsibility for services. This was true both for people residing in the community and for people in the institution.

Third, in August 1989, the waiting lists varied among the ATCs with some ATCs constructing two lists: (1) people who are considered appropriate and accepted but for whom there is no place and (2) people who the agency will not serve. There appeared to be some resistance to making waiting lists available to the state office, although doing so would be a step toward better state planning. The state office reports that the waiting lists are now kept consistently.

Fourth, the ATCs did not know the number of people from their region in out-of-region placements, including people in the institutions, and have no responsibility in this area. Since it is unreasonable for a state office with community services to over

1,400 people to effectively play this type of individual planning role, this reflects a major gap in the system.

Fifth, consistent mechanisms were not in place in August 1989 to insure that children moving from the special education system to adult services were included on the waiting lists. It is our understanding that substantial efforts in transition planning coordination have taken place since that time. In addition, some of the children transitioning from the educational system are reportedly more severely disabled than people currently served by the ATCs. Without continued efforts, these children may end up residing in the institutions.

Finally, while most ATCs have many people waiting for services, others are actually "seeking" individuals with "mild disabilities" to fill spaces in their facilities in order to keep them open. While this involves a small number of people, it points out one of the problems of the current system of "slot allocations" and will be discussed later in this report.

The public institutions. There are several major issues in this area: (1) future of the institutions in the state, (2) the leadership role of the ATCs, the DD Planning Council and advocacy groups, (3) the people in the institutions and their parents, and (4) the institutionalization of a new generation of children in South Dakota.

Consistent with national trends in deinstitutionalization, institutional closure is an emerging issue in South Dakota. In examining this issue, it is important to note that people with similar and even more intense needs than the people currently residing at Custer and Redfield are living in communities throughout the country, including rural areas. The question is not can the people in the institutions be served in the

community, but what are the barriers that are standing in the way in South Dakota from having this occur.

While closure can be justified in terms of benefits to the people remaining in institutions (Lakin, 1989), increasingly it may also be in the best fiscal (Smith & Gettings, 1988) as well as programmatic interest of the state to consider the closure of one of the state institutions and the movement of the people and fiscal resources into the community. In both the United States and in Canada, there is a growing wealth of experience on strategies to reduce institutional admissions, to close institutions with attention to both quality and economic considerations, and to shift funding to the community through methods such as a building-by-building closure plan (e.g., Lord & Heard, 1987; Braddock & Heller, 1984). Key issues in closing institutions are how to build the confidence in the community system of parents whose children are still institutionalized, how to develop a fair and equitable plan for current institutional employees, and how to insure that the community system addresses the needs of people with the most severe disabilities and their families.

For closure to be achieved, it will be important for community leaders, including the ATC directors, the DD Planning Council and the advocacy groups, to play a major leadership role in stressing the importance of developing community services for people currently living in the institutions. While several ATCs are planning to return people home from the institutions, these are important, but small efforts on behalf of a few people. The state's deinstitutionalization efforts must not be viewed primarily as the responsibility of the state Division of Developmental Disabilities.

Several parents, including a parent of a child at Redfield and one at Custer, said that there were no other options available at the time they institutionalized their child.

Although each of the parents felt they could only speak from their own experiences, all were primarily concerned with the welfare of their child: Will our child be safe? Will our child be cared for when we are no longer around? Can we trust and feel secure with the staff? Will our concerns be listened to? Do the staff know how to meet our child's needs? Will there be people in our child's life who care about her/his well-being? These are important issues and concerns that must be addressed. Today, while the choices are better for parents than they were prior to the establishment of the ATCs, there is still no viable family support program in the state and fiscal incentives remain to institutionalize people with severe disabilities.

Finally, this problem is further multiplied by the continued institutionalization of children in South Dakota. While states such as Minnesota, New Hampshire, and West Virginia and large regions such as Macomb-Oakland, Michigan are planning for the last twelve or fewer children to move back to local communities from public institutions, South Dakota continues to institutionalize its children. As of April 1989, over 90 children were living at the Crippled Children's Hospital and School, 20 children in Custer, 25 in Redfield, and additional children in out-of-region placements. Practices for supporting children and their families in this state are out-of-step with national trends and will result in another generation growing to adulthood without early opportunities for integration.

Barriers to supporting people with severe disabilities in the community. The major barriers to supporting people with severe disabilities in the community in South Dakota include: (1) inadequate community financing to support people with severe disabilities, (2) lack of a priority among various agencies and organizations to overcome the barriers that exist in community living for people with severe disabilities,

(3) the need to adapt the community system to be more flexible and responsive to the needs of people with more severe disabilities, and (4) lack of point(s) of regional or local authority and responsibility for deinstitutionalization efforts in the state. In addition, there are other barriers, including policies related to medication and other medical procedures, that must be addressed to support people in typical homes. These barriers will be discussed in other sections of this report.

Recommendation 2A: One of the immediate priorities for the state Division of Developmental Disabilities must be a joint effort with parents and other state and local agencies to support children to remain with families.

Although this report specifically focuses on adults, the future of adult community services also rests largely upon the actions South Dakota will take to promote the community integration of the next generation of children. Most of the changes in adult services in this country are promoted by parents whose children had a right to integrated education. They, in turn, promote integration as their child becomes an adult. According to professionals, "parents lag behind" in South Dakota. It is more likely that parents have come to accept the vision of the future that professionals have given them--one that separates child from family and segregates children with disabilities from other children without disabilities. The development of a family support program should be a key short term goal in this state. In addition, on a long-term basis, South Dakota must initiate more comprehensive permanency planning efforts for all children with developmental disabilities (Taylor, Lakin & Hill, 1989).

While the recommendation on the establishment of a family support program is not controversial, the following aspects of it are: How will these services be financed and how will the responsibilities for costs be shared? What are the respective roles of

agencies once cost sharing arrangements are agreed upon? What does family support mean and how will it be translated into services in South Dakota? Will family supports be primarily agency-determined or family-determined? Although these are complex issues, we would suggest that (1) cost sharing must be the preferred strategy across all agencies involved with children and their families (including the state Division of Developmental Disabilities); (2) the state should reconsider whether Education is the appropriate lead agency for such services given the massive challenges in that area; it is more typical in most states for the DDD to play a leadership role in this area; (3) pilots should be established that explore issues both regarding the services (and payments for goods) and administration of family supports in the state; and (4) the family support pilots should be modeled after the flexible, individualized, family-centered approaches being developed around the country (Taylor, Racino, Lutfiyya & Knoll, 1987).

Recommendation 2B: The Division of Developmental Disabilities should build on the capacities of the Adjustment Training Centers in the state to develop exemplary examples within South Dakota of community services for people with the most severe disabilities.

As mentioned earlier, most of the ATCs have unique strengths that can be further nurtured to create exemplary examples of community living for people with severe disabilities in South Dakota. These efforts must, of course, include adequate funding which will be discussed in the following sections. However, it also means acknowledging the ATCs' own view of their role and supporting the contribution they each can make. As a few examples:

- Instead of sending people from across the state to a "specialized ATC," how could those ATCs be supported to act as a resource to several other ATCs in the state?

- For those ATCs who have helped connect individuals with family, friends and communities, how can those individual efforts be recognized and promoted in the state?
- How can progressive leadership in South Dakota be promoted through incentives to develop community living supports that are not just "okay for South Dakota," but genuinely progressive in the field?

It is important to have examples in South Dakota of community living for people with severe disabilities. As one of the parents whose child is still in an institution stated, "I can't picture it. I would really need to see it." These long-term community living demonstrations should be based upon an "individualized" approach of supporting adults to live in the community, an approach which will be further described in Part II.

Issue 3: Funding for Community Services

Although there are numerous issues concerning funding, this section will deal with the primary one facing South Dakota--the inadequacy of current funding levels for community services. Most of the people interviewed stated that funding for community services in the state is inadequate and must be increased. We strongly concur with this analysis and would like to stress several points:

First, the major need for funding is for direct service personnel to work with people with disabilities in participating in home and community life.

(1) **Number of staff.** The current direct service staffing ratios are inadequate to support many adults with the most severe disabilities in the community. The only exception is that casemanagement ratios (approximately 1 to 20 for people primarily in facility-based services) are good and the roles of these staff could be modified (see Part

II). While we did not do an in-depth study of the issue of professional staff, our data does not indicate an over-reliance on professional staff at the expense of funding direct care staff.

Given the current system of cost reporting across residential-day services, a more extensive analysis of staff deployment across these programs might be worthwhile. As currently structured, a detailed analysis cannot be completed on the residential services without also examining the supported employment/work areas in equal depth. That task is beyond the scope of this report.

(2) **Salaries for direct service staff**. While inadequate pay for direct service staff is a national issue, South Dakota is the first state in our experience where a number of parents also ranked low staff salaries as one of the primary issues facing the service system. There is tremendous concern about the ability of the ATCs to attract good personnel, the high turnover rate (although apparently this is also an issue in the institutions) and the effect this has on the lives of people with disabilities. Some of the ATCs are reportedly having difficulty even competing effectively with entry level positions in fast food chains, although this is variable across the state.

According to a recent study in the State of Minnesota, increases in the average hourly pay of full-time paraprofessionals can reduce the turnover rate as much as 8.66% for every $1.00 increase. The effect of salary raises for professionals and managers on turnover, however, was markedly less (Minnesota Department of Employee Relations, 1989). A number of states are implementing efforts to increase the base wages of community service staff (e.g., Connecticut).

Our study did not examine the wage issue in depth. Although there may be a need within a specific ATC to examine how money is allocated to different salary

classifications, this does not negate the fact that community funding is relatively low. Given that budgets are typically 80%-90% personnel related, such underfunding can be expected to have an impact on the salary levels of direct care staff.

Second, the two primary reasons for the existence of waiting lists for community services are because (1) no funding is available for the individual or (2) the service rate is inadequate to meet the needs of the specific individual. Most of the ATC directors expressed a willingness to support people with more complex needs in the community if adequate funding was available. Several of the directors mentioned that the ATCs are "stretching to the limit" and many more demands will push the organizations to their breaking points. Whether accurate or not, this perception alone could lead to major problems in the delivery of community services in South Dakota.

Third, the only other area consistently mentioned in the interviews regarding funding was the recent cutback in the Medicaid waiver program for areas such as eyeglasses and dental costs that the state Medicaid plan does not cover. While a setback in the state, it appears the Division of Developmental Disabilities has minimized the potential problems to the extent that they could do so.

Finally, the per diems are greatest for the most restrictive settings, such as institutions and least for services provided in homes and more typical community settings. Table 3 indicates the funding sources and amounts for residential program models in South Dakota. In general, the table indicates the traditional pattern of funding with more restrictive, congregate settings for people with disabilities having greater funding available for services than typical homes. As mentioned earlier, this encourages the institutionalization of people with severe disabilities in South Dakota. This and other

funding issues such as inadequate financing for people with severe disabilities, and limited funding flexibility and individualization, will be discussed in Part II of the report.

Recommendation 3A: The South Dakota Division of Developmental Disabilities should seek to increase its funding base for community services for people with developmental disabilities from all sources.

Several initial steps can be pursued to increase the amount of funding available for community services in the state. While these are by no means comprehensive, the recommendations suggest that strategies be pursued on the federal, state and local levels.

One strategy South Dakota could pursue is to increase its rate for home and community-based Medicaid waiver services for people with severe disabilities. South Dakota was one of the early states using the home and community-based Medicaid waiver and has been unable to gain adequate state and federal support to increase its waiver funding levels. As a guide, to deliver the same intensity of services, funding for an individual through the home and community-based Medicaid waiver should be approximately equal to funding for the same individual in an Intermediate Care Facility in the same state. In South Dakota, the waiver rate is less than one-half of that for community ICF-MRs and about one-fourth of the institutional per diems. It is in the best interest of the state, as well as people with disabilities, to advocate with the state legislature to support an increase in the home and community-based Medicaid waiver funding levels (particularly for people with severe disabilities). Organizations other than the Division of Developmental Disabilities need to be aware of the pressures which DDD faces in dealing with the Health Care Financing Administration. As with other states, South Dakota has experienced difficulty in maintaining its current services under

the waiver. When DDD has opportunities to increase funding under the waiver, there must be strong support for this action within the state legislature and other divisions.

A second strategy the South Dakota Division of Developmental Disabilities should pursue is to expand its funding to other state and local sources in addition to its current heavy reliance on federal Medicaid funding. It is an accepted fact in South Dakota that federal funds are a primary source of community services funding. Further exploration is needed, however, on other strategies to broaden the funding base in-state. For example, how and under what circumstances have counties used county tax levies for funding services for people with developmental disabilities? What ATCs have been successful in tapping these funding sources? What coordinated efforts have taken place with counties throughout the state? While the drought has placed additional constraints on local financing, county funding may be a future avenue that remains largely untapped.

It is our experience in many small rural areas that local efforts at solving community problems can benefit not only people with disabilities, but the community-at-large. By joining together to solve a community need (e.g., housing, day care, transportation) existing resources can be better used and disability organizations can contribute to the broader welfare of the community. For example, a need for day care for children with developmental disabilities often reflects a need for day care in the community at-large. Joint efforts can attend to the needs of all children, including those with disabilities, in the town or region.

TABLE 3
FUNDING SOURCES AND AMOUNTS BY RESIDENTIAL PROGRAM MODEL

	PRIMARY FUNDING SOURCE	PER DIEM
1. State Institution		
Custer	ICF/MR	$150.62*
Redfield	ICF/MR	$121.20*
2. Community Residential Facility	ICF/MR	$82.14*
3. CRF (Group Homes)	SSI	$315/month
	HCBS	$40.23**
	Title XX	$11-16***
	Voc. Rehab. 110	$11.16***
	Special Education	$11-16***
	Private Pay	$11-16***
	Out-of-State Payments	Negotiated by ATCs
4. Supervised Apartments (CRF)	Same as CRF (Group Homes)	Same as CRF (Group Homes)
5. Foster Care	SSI and State Supplement	$413/month****
6. Monitored Apartments	Title XX	$11-16***
	Followalong	$98-116/month
	Special Education	$11-16***
7. Independent Apartments	Followalong	$98-116/month
	Special Education	$11-16***

*Estimated January-March 1989
**October-June 1989 Contracts (include day program)
***June 1, 1988-May 31, 1989 (does not include day program)
****Amount if person is in a day program; $484.00/month if person is not in a day program.

As a third strategy, the adjustment training centers, together with the South Dakota Division of Developmental Disabilities, should seek funds from the legislature to increase the base salaries of direct care staff in the state. While the provider association is the appropriate lead agency on this issue, DDD should support requests for moderate increases in salary for direct care staff and work with the South Dakota Association of Community-based Services to influence the legislature to allocate additional funds for this purpose. Both the Association and the DDD may wish to contact their respective organizational counterparts in Connecticut regarding their efforts in this area. Other useful resource people are David Braddock at the University of Illinois where a national study is being conducted on staff salaries, Colleen Wieck at the Minnesota Developmental Disabilities Council and Charlie Lakin at the University of Minnesota who both have a long standing interest in staffing issues. DDD should work with the legislature to insure that these funds are allocated specifically for the purpose of increasing direct care salaries as opposed to administrative salaries or other expenses.

A fourth important strategy is for South Dakota to move toward reallocating funding from institutional to community services. While the institutions are not a primary focus of this report, the South Dakota system is at a point where controversial decisions regarding future directions must be made in order to insure the future well-being of people with developmental disabilities in the state. Given the increasing institutional per diems and probable need for additional capital resources in at least one of the facilities, it is becoming even more imperative to plan to shift financial resources to the community.

In addition to the reallocation of funds from the institution to community services, several states have started efforts where funds are made directly available to

the families as opposed to agencies. This type of individual and flexible effort is being implemented in Rhode Island and could be explored as part of a broader deinstitutionalization and closure plan.

Issue 4: Planning and Communication

There are four major areas addressed in this section: (1) the planning function, (2) the relationship between the ATCs and the state DDD, (3) communication between the ATCs and people with disabilities and their parents, and (4) interagency communication.

Planning. The need for better planning was a predominant theme in both the interviews with the ATC directors and with key personnel in the state office. Several factors seem important in understanding this stress on the planning function:

First, there is a need to recreate a shared vision of the future for people with disabilities in South Dakota. While people use similar words to describe the future--normalization, integration, independence, choices--what this means to different key individuals in the state varies dramatically. In some ways, the differences are most apparent in dealing with controversial issues such as institutional closure. Planning is one way of expressing a need for a shared purpose and shared goals. As Tom Scheinost said, "South Dakota is at a critical juncture in its development of services for people with the most severe disabilities" (Scheinost, 1988). Part of the effort at this juncture must be to recreate a shared vision and to insure that parents and people with disabilities have a central role in creating this vision. The State of South Dakota has embarked on a major strategic planning effort, in part to develop this shared vision.

Second, the community service system has grown tremendously without all of the resources and supports it needs. Planning is a way of recognizing the increased complexity of what community services means today. Planning for a system of this size requires adequate resources (which are not currently available to the state DDD). In addition, from the point of view of a person on the local level, there is a need for better individual and regional coordination and planning (see section on regional control, accessibility and accountability).

Finally, planning is a way of trying to reach agreements and resolve differences. Interestingly, while the ATCs indicate the importance of planning by the DDD, there also is a reluctance on their part to share the necessary information with DDD. Similar tensions exist between the state agencies, especially in areas where fiscal resources are limited.

In many ways, the stress on planning can be viewed positively as an effort to address the tensions in the system and to try to move forward through joint efforts.

Relationship between the ATCs and the Division of Developmental Disabilities. As in most places, there is a range of relationships between private providers and the state office for developmental disabilities with most characterizing their relationship as good. However, several ATC directors noted there is increasing tension between the ATCs and the state DD office. From our perspective, most of the problems seem to stem from the increasing demands of the state office on ATCs (without increasing resources) and the increasing expectations by the ATCs of the state office (also without increased resources). In other words, expectations (rightfully so) have increased throughout the system, but the resources have not kept pace to meet these expectations. In relationship to a major systemwide change, most of the ATCs lack confidence that

DDD will have the resources, the planning capacity and the technical support they would need for broad systemic change. While most agree an "individualized" approach is philosophically sound, they are concerned that this will just be "another idea" that in South Dakota will not become a reality. They feel their current problems are not being adequately addressed and this may result in further expectations that they will be unable to meet given current resources. Despite these reservations, they seem willing to try to do what is in the best interests of the people with developmental disabilities in the state.

Communication with parents and people with disabilities. We were greatly concerned that many interviewees mentioned parents as one of the major impediments to increased community integration of people with disabilities. Given that the current system does not support families to keep their children at home, that institutionalization of children is viewed as a viable option by numerous professionals, and that adequate funding for community services for people with severe disabilities does not exist, it is ironic that "parents" are the ones listed as most in need of education in this state on community integration.

On the positive side, there was a real desire on the part of most professionals to promote better partnerships with parents on issues such as integration and community services. Parent-professional partnerships is a DD Council state plan priority. Parent Connection is training parents in education rights and responsibilities and Guardianship conducts training in a variety of areas, including a recent session on estate and future planning. The Center for Developmental Disabilities applied with the ATCs for a grant for parent training from the Office of Special Education and Rehabilitative Services (OSERS). New local efforts to make current information more accessible to parents are also underway.

Parents are on committees and boards of most of the ATCs. Several of the ATCs have or are considering parent advisory groups. In the interviews, most of the ATC directors mentioned the local chapter of the ARC and one admiringly described the potential of a new parents group which has a strong advocacy focus. Two ATC directors, in particular, spoke eloquently about the importance of "building trust with parents" and "planting seeds (new ideas) early." A few of the ATCs also include positive statements about families as part of their agency philosophy statement. For example, "YAATC views family involvement as beneficial, supportive, and the basis for the development of relationships throughout the individual's lifetime."

On the other hand, one ATC director mentioned it was not the "job" of the ATC to educate parents and that "someone else" should be responsible. This comment was particularly striking when interposed with remarks from a parent whose child was in an institution. She said the director at the institution treated all the parents like royalty. While these are extreme examples, combined with other interview data, they seem to indicate a need for the ATCs to develop a greater focus on supporting and collaborating with families. This is a very different approach than professionals educating parents.

Formal self-advocacy efforts in the state are in very early stages of development. OAHE has a "client council" with a person who works with people in "shaping their own destiny." ECCO has a self-advocacy organization and consumer input is also sought as part of the agency's annual strategic planning process. The ARC is examining the possibility of starting a self-advocacy group. Several ATCs have people with disabilities on agency committees (e.g., Aberdeen, Huron), although no ATC specifically mentioned a person with a developmental disability as a current board member.

Interagency communication between the ATCs and other organizations. With one exception, the ATCs characterize their relationships with the regional offices of the Department of Vocational Rehabilitation as good or improving. They appreciate the Department's new efforts in supported employment. The ATCs have limited or no contact with the county boards of mental retardation and Custer. Their relatively limited contact with Redfield is viewed as positive. One person expressed concerns about the adequacy of the community referral information provided by Redfield; several noted that it was important for more people with disabilities to move from Redfield; and another supported the staff at Redfield and recent positive changes made at that institution. On the local level, the ATCs mainly have contact with the Department of Social Services through foster care placements (which will be discussed later in the report). The relationship with the Department of Health is viewed positively, especially given the monitoring role of that agency. Relationships between the ATCs and the special education services cooperatives are mixed, ranging from competitive to improving to good. Several ATCs mentioned that they "didn't have any" cooperative in their region and several described the cooperative services as "poorly run" and the system as "ineffective." The transition issue is viewed as an emerging issue statewide.

Recommendation 4A: The Developmental Disabilities Planning Council, together with advocacy groups, should consider funding and promoting self-advocacy projects in the state and a series of events to further develop parent leadership and parent-professional partnerships.

Most respondents characterized the parent groups in the state as needing to gain strength. Partners in Policymaking, a project developed by the Minnesota Developmental Disabilities Council, is an excellent example of a way to begin building a strong parent-professional partnership on integration and advocacy issues (Zirpoli, et al.,

1989). Such an effort would complement current endeavors in the state to increase the participation of parents in community living.

Self-advocacy organizations have developed throughout the country and excellent resource materials exist. South Dakota may want to contact organizations that have a long history of self-advocacy (e.g., Oregon's People First) and those which recently started such efforts (e.g., Arkansas ARC). The Center on Human Policy can provide a list of materials available in this area.

While these efforts take time, they are efforts that can influence the future of the next generation in South Dakota.

Recommendation 4B: The Division of Developmental Disabilities, in conjunction with the Adjustment Training Centers, must build a broader base of support for community services in the state and increase efforts to further promote the integration of people with disabilities in community life.

Especially during times of increased stress in the system, it is critical that key people develop joint agreements on major projects to pursue (e.g., the development of family support pilots) and begin to further broaden the base of support for community services in the state. The current effort at "strategic planning" can be one method for agencies, parents, people with disabilities and other citizens to come to an agreement on major directions and strategies for further promoting the integration of people with disabilities in community life. Experience indicates one of the best ways to "educate the public" is to give community members the opportunity to have personal experiences in getting to know individuals with disabilities. One role of federal, state and local government is to enable those opportunities to occur.

Issue 5: Staff Roles, Training and Recruitment

In addition to issues discussed under the funding section, other staffing issues include staff training and development, the role of staff, and staff recruitment.

Staff training and development. The ATC directors generally valued staff training and stressed the following areas as important: behavior management, sexuality, medications, agency and/or normalization philosophy, medical or therapy related issues (e.g., seizures, infectious diseases, CPR), individual habilitation plan or goal writing, and agency policy/procedures orientation. A few ATCs also included more community-oriented areas such as personal and social relationships (e.g., Black Hills) and communication with families (e.g., Brookings) in their training efforts. Except for the philosophy session, most training emphasizes techniques and procedures with a particular emphasis on medical and behavioral practices.

Training varied tremendously among the ATCs. Several ATCs hold monthly inservices and tailor training to needs based upon staff evaluations, observations or survey responses; staff at other ATCs have opportunities to gather only several times each year. There were positive examples of training staff to work with individual people as well as training on a group basis.

The training provided by the ATCs is relatively similar to that provided by traditional facility-based residential services agencies throughout the country. However, areas such as rights and advocacy, participation in day-to-day household routines and relating to the community are not standard parts of the staff training curriculum.

Role of staff. Due to the funding source requirements and past experience with "custodial" staff roles, there is now an increased emphasis on the role of staff as trainer (e.g., a person who "runs" programs). This training role is promoted through policies of

the DDD, such as the language describing services and supports, as well as through job descriptions and policies on the ATC level. As one director stated, "Some people in supervised apartments need to get away from training; we are locking people into eternal training."

It is a positive step to move from "taking care of" people with disabilities to recognizing their potential for growth and development. However, people's full and meaningful participation in home and community life requires a more broadly defined staff role than one as trainer. This does not negate what we have learned about the developmental model, but instead extends this concept to insure that people can live their life fully now (at the same time they continue to grow).

During on-site visits, there was little evidence in facilities of ongoing teaching occurring within the context of day-to-day living. Most teaching seemed to be structured around specific goals in the individual service plans, as opposed to using opportunities during the day to increase people's skills and involvement in the home and community life. During visits to people's homes, staff seldom took advantage of the opportunities to model how one treats guests, to involve people in conversations and to teach basic skills (such as serving one's own food).

In addition to training, the role of staff is also defined as supervision. While this is always a particular concern in residential programs, there seems to be an inordinate stress in South Dakota on the issues of protection and safety. This may be an indicator that sufficient safeguards are not yet developed in the community service system.

Staff recruitment. As mentioned earlier, the recruitment of qualified personnel is a major issue for most of the ATCs. This includes direct service staff as well as professionals. Despite low salaries, without exception the staff members we met and

interviewed at the ATCs were concerned with the welfare and well-being of people with disabilities. While their skills and training varied markedly, each sought in his/her own way to better the lives of people with disabilities. We were particularly impressed with the efforts of one ATC to hire bilingual staff who were aware of the culture of the Native American population in South Dakota.

In working with professionals, the first strategy should be to use community professionals on a consulting basis to work with the direct service staff. As one director stated, "We do not believe in building up specialized services, we use general services." However, at the same time, it may be useful in South Dakota to target professionals (e.g., doctors, nurses, therapists) from across the state for training in working with people with severe developmental disabilities. Although we did not review this issue in depth, there were some indications that current information on supporting people with medical or physical needs (e.g., issues with tube feeding, positioning, adaptive equipment, communicative technology), people with developmental disabilities other than mental retardation, and people with challenging behaviors (e.g., nonaversive behavioral supports) is not widely available. This will be an important area to address if people with the most severe disabilities are to be served in the community service system.

Recommendation 5A: The South Dakota Division of Developmental Disabilities should encourage a broader vision of the role of services and supports in the lives of people with disabilities rather than the current training emphasis.

The role of direct service staff is beginning to change from teacher to a more facilitator role (Knoll & Ford, 1987). In addition, instead of the concept of supervision and training, there is a greater emphasis on the supports that people with disabilities

need to live in the community and the role of staff in individually arranging and providing those supports. While this report cannot discuss these issues in depth, there are a number of efforts DDD can make to start to encourage this change in emphasis within South Dakota. These include:

5A(1): The Division of Developmental Disabilities and the ATCs should develop a process to review their policies and procedures to insure that they reflect both the training and support roles of staff.

The emphasis on the training role is evident throughout the Divisions's and ATCs' policies and procedures. As one illustration, a number of states have home and community-based Medicaid waivers that are written in a way that better reflects principles of normalization and integration of people with severe disabilities. This does not mean that the South Dakota waiver as written is necessarily problematic, but that the language and provider explanation could de-emphasize the medical aspects and include a better balance of training and support. Sample definitions of supportive living from the Minnesota and Arkansas waivers and family education and supports from the Vermont and Minnesota waivers should be considered.

5A(2): The Division of Developmental Disabilities, in conjunction with the ATCs and Triangle group, should develop a process to review their staff training to (a) encourage a support role for staff as well as a training role and (b) insure training includes information on supporting and promoting the participation of people with severe disabilities in community life.

Several of the ATC directors mentioned that the DDD program specialists had been helpful and responsive to them. As part of its technical assistance role with the ATCs, DDD can make available information on new resources in the area of community

living. In addition, the ATCs should be encouraged to review their current training to include ways staff can promote the participation of people with disabilities, including people with severe handicaps, in home and community life. The Triangle group is an example of a coalition that can impact on the entire state by reviewing all aspects of its training. It can insure that information on the support role of staff in promoting the participation of people with severe disabilities into community life is included as a theme in every training event.

As we shift paradigms, personnel preparation is also changing. As one ATC director stated, it is "impossible to keep up with the vast amount of new information appearing daily in this field." Thus, it is becoming increasingly important to shift from training personnel in techniques to preparing staff to problem solve issues within a values framework. For a more detailed presentation of issues in personnel preparation in the 1990s, refer to the chapter on personnel preparation (Racino, in press) referenced at the back of this report.

Issue 6: Quality of Services and Safety

There were a number of major issues related to quality of services and safety that arose during this review. These included the use of AC/DD standards, the role of external casemanagement in the state, and concern for the physical safety of people with disabilities.

First, the AC/DD standards are viewed in the state as indicators of quality as opposed to minimum standards for organizations serving people with developmental disabilities. This misunderstanding of the role such standards play in insuring quality can be an impediment to the development of other essential mechanisms that must be

put in place in South Dakota. As mentioned previously, licensing and/or certification are appropriate when agencies own, lease and operate facilities. The AC/DD process is a reasonable mechanism to use as part of the certification process for facilities. In itself, however, it is an insufficient mechanism for insuring quality.

Second, there seems to be an inordinate amount of concern about the physical safety of people with developmental disabilities both on the part of parents and professionals. This may reflect a reasonable fear (for example, "followalong has kept some people from becoming homeless people") of people being placed in situations without adequate services and supports, in homes that are unsafe, and without mechanisms to insure their well-being and safety. There are no "guarantees" or "infallible approaches" to insuring quality, but multiple approaches offer the best promise. Certainly it is appropriate to regulate basic safety and rights protections wherever people may live. Neither the DDD or the ATCs should pursue strategies that place people with disabilities in unsafe conditions.

Third, the issue of external casemanagement should be examined in conjunction with the following three areas: (1) the future direction regarding the structure of community services in the state (see recommendation 1A), (2) the future state direction regarding non-facility-based services (see Part II), and (3) the separate functions involved in the term external casemanagement (Lippert, 1986). Although the overall plan should vary depending upon this analysis, at least some of the casemanagement functions should be located external to the provider agency.

Recommendation 6A: The South Dakota Division of Developmental Disabilities should implement a more comprehensive framework of quality assurance to promote the well-being and participation of people with developmental disabilities in community life.

Attached in Appendix IV is a conceptual framework for thinking about the multiple mechanisms involved in insuring quality. This framework differentiates facility-based and nonfacility-based services which require different strategies, an issue currently inadequately addressed in this field. Examples of a number of quality assurance mechanisms outlined in the conceptual framework currently exist scattered throughout South Dakota. These can be the base to build further efforts in this area:

- South Dakota guardianship project
- Citizen advocacy programs (e.g., Huron, Brookings)
- South Dakota advocacy project
- Agency evaluation committee that includes people with disabilities and parents as well as the staff and board members (e.g., Yankton)
- Family advisory board and self-advocacy as part of annual strategic planning

The Center on Human Policy can assist the DDD to implement the framework described in Appendix IV, in conjunction with a wide range of other agencies, organizations, parents and people with disabilities. In the interim, DDD should encourage the ATCs to develop quality of life standards similar to that of Options in Community Living, a private, non-profit agency supporting adults with developmental disabilities in the community (see Appendix V).

This recommendation is not meant in any way to imply that DDD has done an insufficient job in its role in quality assurance. In fact, the use of AC/DD standards, the vigilance of DDD and the commitment of the ATCs has resulted in a current system that addresses the basic elements of rights and safety.

Issue 7: Community Integration

Before we can discuss issues regarding an "individualized" approach to supporting adults in the community, it is important to first examine how South Dakota is implementing its current goals of normalization (now known in this country as social role valorization) which is the foundation for further individualization within the system.

First, on the area of ***physical integration*** into the community, there are several central issues.

(1) **Size of homes.** South Dakota is to be commended for minimizing the development of community institutions over the size of 15 people. However, the average size of community residences built in South Dakota (approximately 10) continues to be much larger than current national trends. Again the state DDD should be commended for recent changes that will reduce the size of future residences.

(2) **Concentration of facilities.** Overall, many of the facilities in the state are concentrated in near proximity to each other. It is relatively common to have monitored homes attached to group homes, or homes located next door to each other. This greatly minimizes the potential for integration of people with disabilities.

(3) **Development of segregated facilities.** One of the recent trends in South Dakota is the building of segregated apartment buildings for people with disabilities. Although providing people with more individual privacy than most group living facilities, the buildings limit opportunities for contact with "nondisabled" people. There appears to be limited recognition of the problems inherent in this type of segregated approach. On the other hand, most of the monitored apartments appear to be more integrated into the community.

(4) **Use of vans.** This is a more complex issue because of the transportation problems in a number of areas in the state. However, some towns have found and encouraged other more integrated solutions to the transportation problems. These strategies could be more widely implemented in the state.

(5) **Prevalence of segregated work and recreation options.** While there are commendable efforts in areas such as supported work (given the barriers that exist), most of the options for people in the state remain as segregated ones. Several people mentioned that integration is "not as good as it should be, but we are working at it."

The above are listed as general themes from the visits and interviews and do not apply to all the ATCs, a number of which are very conscious of the importance of physical integration and have made exemplary efforts. In the area of physical integration, strengths in South Dakota include:

(1) **Appearance of homes.** In general, the homes and apartments fit in quite well with the neighborhoods except for specially built homes which often had a sign in front of the homes. Generally, the homes appeared well kept.

(2) **Location in residential neighborhoods.** The homes and apartments were located in typical residential neighborhoods as opposed to industrial or other business locations. Several ATCs, such as Aberdeen, mentioned this as a positive step toward integration.

(3) **Location near to community resources.** Most of the locations of the homes seemed to indicate an awareness of the importance of locating homes near other community resources.

(4) **Supported work and followalong.** When given new opportunities, and sometimes despite many barriers, many of the ATCs have developed options that

promote greater physical integration and the potential for social integration in the community.

The second area includes ***major issues in supporting people to be a part of their home and the community.***

(1) **Transition and readiness.** As indicated earlier in this report, especially for people with severe disabilities who may not generalize well, the concept of preparing in one environment (e.g., a group home) for another environment (e.g., an apartment) is not the most useful way to design services. Instead, current emphasis is on starting where the person will live (i.e., a regular home) and teaching within that home environment. South Dakota's eligibility and exit criteria and the design of facilities continues to place an extremely high emphasis on physical movement as an indication of greater independence.

(2) **Home and program.** There is a natural tension that exists in providing services in a person's home. This tension does not sufficiently exist in South Dakota where community residences are seen first and foremost as programs and only tangentially as people's homes. As the director of a larger ATC stated, "the message to people is you are here to receive training even though it appears to be your own apartment. Once at Step 5, we will kick you out and help you find your own place." Thus, the homes are viewed as training facilities with the main emphasis on the program and on skill building. In some ways, "community residential facility" does more accurately describe what has been created in South Dakota as opposed to the words "group homes." South Dakota needs to reinstill the tension between home and program, through a greater emphasis on the meaning of home.

(3) **Community participation.** Despite many of the existing physical barriers to integration, a number of agencies should be commended for their efforts to promote the participation of people with disabilities in community life. For example, one ATC has policies that promote people participating individually or in small groups (3 or fewer people) in local activities. At South Central Area ATC, staff are helping to integrate people into the Jaycees, Lions, Lionettes, local churches and other community groups. As the director explained, "This has benefited both the clients and the community. People develop relationships. This happens because our staff are in these organizations and they encourage other people to (do things like) give rides." The Southern Hills ATC also strives to involve Native Americans in cultural activities such as participation at the Loqata chapel. These are examples that need to be encouraged and supported by the DDD and disseminated throughout the state.

(4) **Relationships and program.** One of the highly discussed topics in this field is the relationship of people with disabilities with typical community members. Both parents and the ATC directors mentioned the importance of relationships and friendships. Others expressed the same issue through their concern about the potential isolation of people, especially if they lived in monitored apartments. The emphasis on training prevalent in the community residential facilities has overshadowed the importance of the development of relationships. This balance must be reassessed and strategies for promoting the importance of relationships should be pursued.

Recommendation 7A: The South Dakota Division of Developmental Disabilities, in conjunction with the Association of Community-Based Services, should implement a concerted effort in providing values-based training in normalization (now known as social role valorization) and its implementation for both direct care staff and management.

There is a need in South Dakota for training of both management and direct care staff in the basic principles of normalization and residential services development. Primary issues that need to be explored include:

* a better understanding of the relationship between physical and social integration of people with disabilities,
* the meaning of home and the context of services in a person's life,
* ways of promoting social integration of people with disabilities,
* the concept of model coherency--how does it all fit together?

Better grounding in these principles will be critical before efforts to support people with disabilities in more individualized ways can be addressed statewide.

It would also be useful to arrange for updated, intensive advanced training for a selected core group of trainers. Trainers need to be better tied into national networks to insure that South Dakota has access to information on program evaluation instruments (e.g., PASSING) based on normalization, new training (e.g., Framework for Accomplishment), and other important developments. The Center on Human Policy can provide training in community integration and other support service issues. However, there is well-developed training in social role valorization and other normalization areas available through the Training Institute on Human Services Planning at Syracuse University; this would also be applicable to the present needs of staff in the state.

Recommendation 7B: The state Division of Developmental Disabilities should explore a variety of incentives for community integration in homes, in work and in recreation.

This is an extremely problematic area for the Division of Developmental Disabilities due to its limited financial resources. It is critical, however, to explore

mechanisms that encourage organizations to move toward integration. These can include: higher payments for more integrated services, new funding focused on more integrated options, and highlighting the efforts of ATCs in community integration in the state.

SUMMARY: STRENGTHENING THE CURRENT SYSTEM

This section of the report described critical areas to address whether or not the Division of Developmental Disabilities and/or providers decide to proceed with an "individualized," "housing/support" or "person-centered" approach to supporting adults in community living. Although many of the issues discussed in this section are known to those most intimately involved with community services for people with developmental disabilities, part of the intent of this report is to make this information accessible to a broader range of people.

In addition, some of the recommendations are necessary (e.g., training in normalization) as the basis for any major systemic changes in residential services in South Dakota. If the preceding issues are not addressed, the current problems in the system will become even more evident in moving in the direction of more "individualized" supports.

The current system has many strengths to build on as these recommendations are pursued to further develop South Dakota's residential service system for adults with developmental disabilities. The DDD should take steps to start addressing each of the seven major issues described in Part I.

PART II: MOVING INTO THE 1990s: HOUSING/SUPPORT SERVICES APPROACH TO COMMUNITY LIVING

Background

This section of the report will examine issues that South Dakota will face in implementing an approach to supporting adults called an "individualized", "housing/support" or "person-centered" approach. As noted in Figure 3, this individualized approach includes these primary service characteristics: separation of housing and support services, housing and home ownership, close ties among individual assessment, planning and funding, individualized and flexible supports and consumer-directed services and housing.

FIGURE 3

SERVICE CHARACTERISTICS OF A HOUSING/SUPPORT SERVICES APPROACH

Separation of Housing and Support Services

Home Ownership and Housing

Individual Assessment, Planning and Funding

Individualized and Flexible Supports

Consumer-Directed Services and Housing

As described earlier, an individualized approach is based on the principle that adults with severe disabilities can live in typical homes in the community with the necessary supports. This approach has been pioneered by agencies such as Options in Community Living in Madison, Wisconsin (Johnson, 1986) and Centennial Developmental Services in Weld County, Colorado (Walker & Salon, 1987). Each of

these agencies support more adults in the community than the number of adults served by any individual ATC. Aspects of an individualized approach can also be found on a regional or statewide basis, including in North Dakota's individualized supportive living arrangements (ISLA) program (Smith & Alderman, 1987; Racino, 1988), Wisconsin's individualized services option (ISO) program (Taylor, 1987), Michigan's supported independence program (Taylor, 1985), and supports for adults in New Hampshire (Biklen, 1989), Minnesota (Racino, 1989), Ohio (Shoultz, 1989), and Colorado (Smith & Alderman, 1987; Walker & Salon, 1987). Numerous states have also established demonstration projects on variations of this supportive living approach within the past few years (e.g., Arkansas, Maryland, Ohio, Florida).

This section of the report examines steps South Dakota can take to incorporate these emerging directions in community living for adults with disabilities. The issues described in Part I form the essential foundation for further changes and development. In moving to this approach, it is essential that (1) mechanisms are in place to encourage quality and protect the basic rights and safety of people with disabilities; (2) there is a strong foundation and understanding of normalization in the system; and (3) adequate financing is made available so people will receive the supports they need. In addition, some aspects of this approach cannot be implemented unless (1) there is a local or regional mechanism for control, accountability and accessibility by parents and people with disabilities; and (2) parents and people with disabilities obtain more input into service directions.

Although Part II will describe a variety of individual strategies, the major recommendation is as follows:

South Dakota should establish long-term demonstrations in supporting people with severe disabilities in community living using an "individualized approach." These projects should be used to identify and address specific systems barriers, to build the capacity within the state to support people with severe disabilities individually and flexibly, and to explore new options in housing and support financing.

At the same time these projects are occurring, the state Division of Developmental Disabilities can work to develop a broader Constituency in support of community living and to address the other essential issues described in Part I of this report. The following issues and recommendations describe some specific areas the Division can examine in moving toward an "individualized" approach in this state.

ISSUES AND RECOMMENDATIONS

Issue 8: Separation of Housing and Support Services

To increase flexibility and individualization, the housing and support components of "residential services" must be separated. Thus, people with disabilities, whether single or married, can have access to a variety of support services, regardless of where they live (Johnson, 1986; O'Brien & Lyle, 1986; Taylor, Racino, Knoll & Lutfiyya, 1987). While housing should be separate from support services, an agency might assist people in locating housing, signing leases, negotiating with landlords, arranging for architectural adaptations and obtaining subsidies (Taylor, Racino & Rothenberg, 1988).

Figure 4 delineates housing options based on who owns or leases the home and a variety of paid support options. The reader is referred to our study of private community living arrangements in Connecticut for a more detailed description of these housing and support options. Such an approach increases the individualization and

flexibility in community living for people with disabilities, since any housing and support option can be combined. This figure is not comprehensive, but illustrative of a way to think about the separation of housing and support services.

FIGURE 4

AN INDIVIDUALIZED APPROACH TO COMMUNITY SUPPORT

Separation of Housing and Support

Housing Options	Support Options
Own Home	Agency staffing
Parent's or guardian's home	Live-in
Shared home	On-call
Existing home and households	Other
Cooperative	Paid roommates or companions
Corporation owned or rented	Paid neighbor
	Attendant

*From Taylor, Racino & Rothenberg, 1988, A Policy Analysis of Private Living Arrangements in Connecticut

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In moving from a facility-based to a "housing/support services" approach, one of the first questions to ask is "What are the impediments in the current system to providing supports to people with disabilities wherever they may live?" Typically, the impediments fall into the following general categories although the specific barriers vary from state to state:

Financing for housing and support services bundled in one package. To a large extent on the state level, the funding categories of community living training, the home

and community-based Medicaid waiver (HCBS), and followalong/outreach are distinctly separate from housing financing (except for areas such as debt financing, utilities, etc.). Thus, little dismantling is required on the state level in this area in moving toward a more individualized approach to supports.

DDD has recently changed from using Title XX funds to general state funds. This is a positive step and will increase its ability to use these funds flexibly and individually. ICF-MR funding, however, must be used for facility-based services and cannot be used to fund "individualized" services. The DDD is moving away from the use of ICF-MRs to a greater reliance on HCBS which can be used to support aspects of an individualized approach (see Appendix VI). Of course, any Medicaid funding, including HCBS, has restrictions on its use particularly in areas such as stipends.

Because South Dakota providers own many facilities with long mortgages, existing funding for support services is not as flexible at the agency level. Current funding is necessary to continue to keep existing facilities financially viable. Achieving this approach statewide will require long-term plans and strategies on the local level with support from the state DDD regarding the future of existing facilities.

Legislation, regulation and/or other policies prohibiting services from being provided in people's own homes. It appears that no major legislative changes are necessary to permit people with disabilities to obtain support services in their own home. Followalong services, for example, can already be provided in a person's own apartment. An individualized approach, however, would involve the provision of more intense services, including 24-hour supports within a person's own home.

A number of policies and regulations may need to be revised and/or interpreted in a broader way. For example, South Dakota should examine the following:

(1) Will the current home and community-based Medicaid waiver allow services to be provided in a persons "own home"?

(2) Can funds from different sources (e.g., HCBS and foster care; HCBS and state general funds) be used for the same individual?

(3) Are there definitional limitations on where services can be provided?

Combining of the roles of landlord and support services provider. The private providers in South Dakota, with the encouragement of DDD, have invested heavily in the development of specially-built facilities. A number of directors described facility development as an important part of their role. There is also a strong emphasis on the part of many of the ATC directors on their agency role as landlord. Many of the facilities have 30-50 year mortgages. Some of the facilities reflect a community effort to try to meet the needs of people with disabilities, and there is a community investment in maintaining the facilities.

Recommendation 8A: The South Dakota Division of Developmental Disabilities should review its policies and procedures to allow adults with disabilities, whether married or single, to receive support services in their own home.

This recommendation should be implemented only in conjunction with the recommendations on quality contained in other sections of this report. This is important to insure the safety and well-being of people with disabilities during this change process.

As noted earlier in this report, there is a growing concern in South Dakota on how to support parents with developmental disabilities. In addition to barriers to supporting individuals in their own homes, the situation of married couples, including parents, also should be addressed. The same basic decision-making process applies, whether a person is married or single (see Figure 8). The major difference is that there

must be a family-centered as opposed to an individual-oriented approach to decision-making and to providing support services. With families, more agencies also tend to be involved and responsibilities are not always clear. In order to implement this approach for parents with developmental disabilities, there is a need to develop better interrelationships with social service agencies that provide early intervention, intervene with children at possible risk or provide other family services. For example, one agency mentioned that two couples married and the "Department of Social Services took over with home health aides." Another person was terminated from services when she had a baby because she could not continue living in the supervised apartments. In yet a third situation the ATC director simply said, "we don't do babies." One of the primary issues will be working out shared roles and responsibilities in supporting families, including those with parents who have a disability.

Long-Term Recommendation 8B: The Division of Developmental Disabilities, in conjunction with the Adjustment Training Centers, should begin to examine the separation of the Adjustment Training Centers' current roles as landlord and service agency.

While there are conflicts between the roles of landlord and service provider, the separation of these roles in South Dakota should take place gradually over time. On a short-term basis, such a separation of roles should not be required, but encouraged by the Division of Developmental Disabilities. The primary strategies the Division should use are to (1) encourage the providers to separate the landlord and services roles in the new development of housing and (2) begin investigating home ownership and leasing by people with disabilities.

8B(1): As discussed in the housing section, the DDD can encourage the use of private investors and housing associations to develop new housing and local landlords to provide existing housing, thus eliminating on a long-term basis the conflicts between the ATCs' current roles as landlord and service agency.

8B(2): As discussed in the housing section, the DDD should explore its role in supporting the ownership and leasing of homes by people with disabilities and their families.

Issue 9: Individualized and Flexible Supports

An individualized approach focuses on support strategies as opposed to supervision and an almost total reliance on paid, shift staff. These support strategies may include paid support, such as live-in, on-call or drop-in staff employed by an agency and hired specifically to work with the person, paid roommates or companions who may be self-employed, an attendant hired by a person with a disability, or a person who lives in the neighborhood and receives payment for services (Taylor, Racino & Rothenberg, 1988). Support strategies also can include the use of physical adaptations (e.g., automatic door openers), routine modifications (e.g., listening to a tape recorder), and the fostering of unpaid support (Walker & Salon, 1987).

In examining the issue of individualized and flexible supports, there are several primary areas to review within the service system:

The types of services and supports available and fundable. As in most systems, South Dakota has focused its services on the provision of training and supervision by agency-employed staff. We found no examples of services and supports provided by an attendant hired by the person with a disability, paid roommates or companions, or hiring

of staff specifically matched to work with one particular individual. As noted previously, there was one example of the use of a stipend to pay a neighbor.

Our interviews indicate while ATC directors are generally open to the use of stipends, several are concerned about training the neighbor. In other words, instead of a different form of support, a number of directors saw stipends as another way to train/hire staff responsible to the agency. Discussions are needed about the rationales and dilemmas of these alternative strategies before they are encouraged by the state DDD.

In addition, personal care assistance services are reportedly limited in the state and generally not accessible to people with developmental disabilities. The DDD and the ATCs are typically not aware of these services since they are viewed (and apparently designed) only for people with physical disabilities. Advocacy organizations and those who work with people with physical impairments report the need to increase the availability of these services which are administered by the Department of Social Services in the state.

Most of the services that are available through the ATCs involve training of the person with a disability. Therefore, supports to others living in the home (e.g., respite) are generally not available. In some remote rural areas, there is a need for medical, therapy and other professional personnel. Advocates report a lack of financial assistance to purchase medications. Transportation is a primary issue due to the largely rural nature of the state.

There are creative examples in South Dakota of physical adaptations, such as the use of a tape recorder describing a person's morning routine. However, needed adaptations are not always available (e.g., electric door opener) and those that are

available are not always effective (e.g., telephone adaptation). One director noted "it's a tough life for people in apartments. Some can't even open the door to get out." It is a very serious concern for people with disabilities to be faced with this unsafe situation, especially since the technology is available to address it. Another director reported it is currently the responsibility of the ATCs to fund any piece of equipment and pay for "rehabilitation engineering" up to $300. Several advocates mentioned that block grant funds were too limited for adaptive equipment.

Most of the ATC directors reported that the funding system was flexible enough to pay for a wider range of support services than was currently used. While a variety of services are fundable under current funding sources, current policies and existing facilities may stand in the way of making available flexible and individualized services and supports.

Barriers to providing specific supports in-home. Even if supports are fundable, there may be barriers to providing these supports within a person's own home. For example in South Dakota, while the state Nursing Practices Act does not directly place limitations on people with medical needs living in their own homes, due to its requirements on who can provide medical services, defacto limitations exist for community living for people with medical needs. Other states have addressed this emerging national issue through revised regulations (e.g., Oregon) or through waivers granted by the state nursing board (e.g., Idaho) on who can be trained to provide specific in-home services to an individual.

Individualization of supports. As will be described in the section on individual planning, assessment and funding, South Dakota generally supports individuals within the context of existing facilities. Except for people with mild disabilities who obtain services

in monitored or independent apartments, there is limited experience in the system of supporting adults in more individualized and flexible ways. For a good description of the development of supports, the reader is referred to the manual Belonging in the community which describes an innovative support agency in Madison, Wisconsin.

Many interviewees mentioned that Title XIX requires 24-hour supervision, but "some of the people don't need that, could be more independent." While Title XIX ICF/MR facilities must have 24-hour supervision, it is unclear whether this federal requirement applies to people funded through the Title XIX Home and Community-based Medicaid waiver. Certainly individuals living with their families can receive services for only a portion of the day under the HCBS waiver. A number of states do, in practice, fund services on a less than 24-hour basis through the waiver for adults living in their homes (e.g., North Dakota, Colorado). Other states, however, will fund family services on a less than 24-hour basis, but define their supportive living arrangements for adults under the waiver as 24-hour supervised places (e.g., Minnesota). In places like Minnesota, though, if people need less than 24-hour services, they can stay in the same home with the same staff, but the financing will change from the waiver to a state-county funding source.

Monitored apartments can be more individualized than other options although the intensity and frequency of supports is limited by the $16.00/day maximum payment rate. Compared to any other option, monitored apartments were often described as providing different services depending upon the person and their needs. Staff were described as having different roles ranging from working on cleaning and shopping to participating in social events with the person. In one of the monitored apartments visited during this review, we were impressed with the casual and natural ways that staff

supported and worked with people in their apartments. One support staff explained how he had adapted his life to flexibly meet the changing needs of people in the monitored apartments. Cautions regarding the monitored apartments include: (1) several are designed as cluster apartment models and have some of the same issues associated with group homes (for a fuller discussion of clustered apartments, see Taylor & Racino, 1987); (2) the monitored apartments can only support people with more mild disabilities; (3) many of the monitored apartments are designed as transitional steps to people's own places; and (4) some are operated as agency facilities as opposed to being people's own homes.

Individualization also means taking into account an individual's cultural and ethnic heritage. With the large Native American population in South Dakota, it becomes very important to develop strategies that are responsive to their unique cultural heritage. While we found some good examples of efforts by one ATC to be aware of and work within an Native American cultural framework, this remains as a major unaddressed area in South Dakota.

Flexibility of supports. South Dakota's system of services is flexible in the sense that staff can be deployed across settings on a short-term basis in emergencies. Agencies seem to have enough flexibility to build in mechanisms to respond to short-term crises. The agencies report, however, that they are not able to combine funding across different funding sources and this hampers their ability to respond individually and flexibly to people's needs. There also seems to be no mechanism in place to respond to longer-term crises, such as the temporary services fund in Connecticut or the exceptions payment mechanism in Michigan. Instead,

institutionalization may be the response. While agencies have at least some flexibility, there is little if any flexibility for parents and people with disabilities.

The role of service coordination. The casemanagement role traditionally has included the following components: assessing, planning, monitoring, evaluating and advocating. In implementing an "individualized approach," however, it is critical to move toward a service coordinator role where the casemanager (a) has increased responsibility, (b) plays an active "hands on" role in developing services and supports if these are not available for the individual, and (c) coordinates services and supports which may be obtained from a variety of different human service organizations, community agencies and/or individuals. The role of service coordination is a critical aspect of this type of approach.

To be able to act on behalf of the individual, it is essential that most components of this role (particularly monitoring, evaluating and advocating) are located outside the service provider agency. Although South Dakota has a limited number of private providers, external casemanagement will allow for effective service monitoring and also increase options for people to obtain services from other people and organizations than the ATC.

The role of service agencies. The traditional role of services agencies and the role of agencies using an "individualized approach" are very different. Figure 5 contrasts the traditional role of a residential service provider with an agency using a support services strategy.

Thus, full implementation of this approach will require a major change in the role and structure of each of the ATCs. These changes can occur gradually over time. In the long term, agencies must re-examine almost every aspect of their organization. In traditional organizational language, these aspects include: basic values and philosophy;

FIGURE 5

Traditional Role of Service Agency

* To evaluate the strengths and weaknesses of a client, to identify needs and implement a program to remediate deficits, and to prepare him/her to move on to the next higher level of independence; to monitor his/her actions and development.

* Landlord

* Responsible agent for client's well-being and progress.

Support Services Agency

* To provide a system of supports for as long as they are needed to enable the client to successfully live in a home of his/her own in the community and to gain more confidence with things in life that are meaningful to him/her.

* Helper, advisor, facilitator and advocate.

Johnson, 1985

staff roles, evaluation, training, support, staffing design; agency design and structure; management role and dispersed services management; financing; quality assurance; service design issues including assessment, planning, supports, and casemanagement. This report cannot describe all the details of this process. In some ways, on an agency level, changing this approach has similarities to conversion of an agency from a sheltered work provider to an agency providing only supported work. The Center on Human Policy and organizations such as the Human Services Institute in Maryland and Responsive Systems Associates in Georgia are resource organizations to assist with these changes; other private agencies involved in this "conversion" or "inversion" process can also be a good resource.

Monitoring supports. Another critical issue is the monitoring of supports and services in a variety of homes located throughout the community. The framework described in Appendix IV also addresses a non-facility-based approach to services and includes a variety of formal and informal approaches including empowered casemanagement, requirement for quality of life guidelines with procedures, requirement for agency self-evaluation, citizen advocacy and citizen reviews, as well as a variety of informal mechanisms.

Recommendation 9A: The Division of Developmental Disabilities should broaden the types of support available to people with severe developmental disabilities.

The DDD needs to encourage the ATCs to develop support strategies as opposed to placing people in facilities. As agencies pursue support strategies, issues generally arise in at least these areas:

* How can people with developmental disabilities access personal care assistance in their homes on an extensive basis?

* How can agencies find, arrange and pay stipends to individuals who may not be employed by the agency?

* What other supports besides staff can be used and how can these supports be arranged?

As initial steps in broadening the range of supports in South Dakota, the following recommendations are made:

9A(1): The Division of Developmental Disabilities, in conjunction with other state agencies, should examine the options for expansion of personal assistance services in the state, including for people with severe developmental disabilities.

9A(2): The Division of Developmental Disabilities should explore options for funding emergency devices and other mechanical aides that could be used to support people in their own homes.

9A(3): The Division of Developmental Disabilities, in conjunction with the Adjustment Training Centers, should explore other approaches to supports beside paid agency staff (e.g., stipends).

These steps will assist both the DDD and the ATCs to broaden the way they think about and develop support strategies. Personal assistance services can be a Medicaid state plan option, can be included as a service under the Medicaid waiver, and structurally should be designed in the state to be accessed by people across disability groups. If the state DDD moves toward an approach of mixing funding sources based on the type of services a person requires, the state general funds could be targeted for use for stipends or other non-traditional services that are not fundable through sources such as Medicaid.

This report cannot detail all the steps in developing individualized and flexible supports for people with disabilities. Our experience indicates that the best strategies for promoting these changes on the local level are: (1) creating opportunities for providers to meet with other providers who have experience in developing support strategies; and (2) for providers, administrators, parents and people with disabilities to visit other agencies using a support services approach.

The major roles of the state in this process are: (1) encourage and support creativity on the part of the providers in meeting individual needs; (2) address system barriers as they are identified through the development of individualized support strategy plans; (3) make possible the use of other "non-traditional" supports; (4) insure

adequate funding and resources are available for demonstrations; and (5) work together with a broad range of organizations and individuals to translate the learnings from the demonstrations on a systemwide basis.

Long-Term Recommendation 9B: The roles of the Adjustment Training Centers should be redefined to better support people with severe disabilities in the community.

As described earlier in this section, as organizations change to supporting individuals in their own homes, changes are also needed in the structures of agencies and roles of staff. In South Dakota, organizations can begin to explore these changes by examining the role of the direct service staff and their agency organizational structures. In the future, organizations can develop individual agency "conversion" plans, but a firmer foundation in an "individualized" approach and what it means in practice is necessary before such efforts can be meaningfully undertaken.

The immediate issue here is to provide opportunities for people to begin to understand the differences between the current approach and an "individualized" approach. Based on our interviews with the ATC directors, the concept is still very new and generally misunderstood. As in any paradigm shift, people will keep fitting the new changes into their traditional way of designing services. Finally, the "pieces" will no longer fit and the individual recognizes the fundamental distinctions between the approaches. To date, our experience in states indicates that this "breakthrough" occurs for different people at different times; it can be gradual or immediate; and happens best through direct experience and in an atmosphere that encourages people to be creative. While the language of individualized services may be easily adopted by agencies, this does not necessarily reflect that a substantive change has occurred at the agency level.

Again, in these areas the role of the DDD is to encourage creativity on the part of the agencies, not to mandate these changes.

9B(1): The role of direct service and administrative staff at the Adjustment Training Centers should be revised to a support services approach.

9B(2): The role of the Adjustment Training Centers should be redefined as support service agencies and organizational structures reviewed for necessary changes.

Some of these changes will be very difficult for the ATCs and DDD to consider given the heavy emphasis on training, the generally hierarchical nature and division of functions in the ATCs, and the fundamental changes this requires.

Recommendation 9C: Casemanagement should be implemented as a service coordination role and should be located outside the provider agency.

Based on our interviews, the caseloads of casemanagers are generally about 1 to 20 at the ATCs. This is similar to the service coordination ratios being used in developing more individualized supports for adults and family-centered supports for children. A member of the steering committee for this project in South Dakota mentioned that to implement an individualized approach would require finding new people to "beat the bushes" to connect people with disabilities with existing community resources. While other staffing ratios may be inadequate, these casemanagement ratios should be sufficient for these community-focused efforts to be part of the role of the casemanager (provided the casemanagers work within a shared team concept).

In addition, several interviewees mentioned the importance of moving the casemanagement role outside the provider agency. As described previously, "empowered casemanagement" requires that the "monitoring, evaluating and advocacy" functions be external to the agency. Although other service coordination functions (assessment,

planning) can be accomplished internal to the organization (e.g., Minnesota), this often results in the person with a disability needing to obtain his/her services from this one organization. On an immediate basis, the ATCs could continue to carry out the functions of assessment and planning if the ATCs move toward developing other options besides their own agency services. However, plans should immediately be developed for shifting minimally the monitoring, evaluating and advocacy functions external to the providers.

Short-Term Recommendation 9D: Division of Developmental Disabilities should work in conjunction with other agencies, families, and people with disabilities to establish demonstrations on individualized and flexible supports in the state.

There is very little individual or collective experience in the state in implementing individualized and flexible supports. Many of the ATC directors were unfamiliar with the concept and current discussion in the field on family supports. It is our experience that it is usually easier to begin understanding issues of support strategies through projects that provide individualized and flexible supports to families. The issues of supporting adults are much more complex and experience in the family support area can be a good foundation for further work with adults (although there are also fundamental differences between supporting adults and children which cannot be discussed in depth here).

Recommendation 9E: The Division of Developmental Disabilities should work collaboratively with other organizations to eliminate barriers to providing supports in people's own homes.

Shifting to this approach usually necessitates greater work with other Divisions and organizations in the state since the traditional lines of responsibility become

"blurred." This may become more complicated in South Dakota where responsibilities of state agencies are already unclear. Approaching this issue from an optimistic framework, examining individualized supports may provide an opportunity for South Dakota to clarify roles and responsibilities between state agencies.

The most immediate interorganizational issue that will need to be addressed is as follows:

9E(1): The Division of Developmental Disabilities should explore with the state nursing board options to allow "unlicensed" individuals to be approved on an individual basis to provide necessary medication and other supports in-home.

The DDD has already worked successfully with the board in the past and other states have succeeded in obtaining waivers (e.g., Idaho) or revised regulations (e.g., Oregon) that allow for medications and other procedures to be performed by non-nursing personnel for specific individuals. The DDD should also contact individuals interested in technology-assisted children in South Dakota. Based on our experience in other states, respite workers for parents of these children are likely to be facing the same problem in the state.

Issue 10: Housing and Home Ownership

Increasingly, home ownership and leasing are becoming an option for people with disabilities and their families (e.g., Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, 1988). Although a variety of strategies exists to enable people with disabilities and/or their families to obtain affordable, accessible and decent homes, their potential remains largely untapped. These strategies include the development of private cooperatives, the use of trusts for housing, housing subsidies, the purchase of homes

through housing associations, and the creative use of low income tax credits and other financing for housing, among others (Racino, in press).

There are three major issues addressed in this section of the report. The first is the availability, accessibility and affordability of general housing in South Dakota. The second is the extensive mortgages and buildings currently owned by private service providers in the state. The third is the promotion of home ownership by families and people with disabilities.

Availability, accessibility, and affordability of housing. Most ATC directors were only broadly familiar with the community housing situation in their region. Based on their reports, decent housing in South Dakota generally falls into these categories: (1) available and affordable or (2) available but not affordable. In addition, most reported the wide availability of affordable, but substandard housing. As described by the ATC directors, the major problems with existing housing were either that individuals with disabilities could not afford the housing or that the housing was not considered safe or decent. Several directors mentioned that the cost differential between low income housing and other available housing was substantial. This factor needs to be further explored in deciding about housing subsidy programs. Figure 6 illustrates the responses by some of the ATC directors regarding the housing situation in their region (though some responses referred to the town in which the ATC was located as opposed to the region as a whole).

In asking the directors about Section 8 housing vouchers, most were familiar with the use of Section 8 in congregate living situations, but had little information about its use in apartments or homes leased by people directly. Some directors inaccurately believed Section 8 could only be used in congregate buildings or in designated

FIGURE 6
Affordability and Availability of Decent Housing*

Affordable and Available	Available and Not Affordable
x Winner	x ATCO
x Chamberlain	x Black Hills
x Aberdeen	x Brookings
x Huron	x Sioux Falls
x ECCO	x Live Ctr.
	x OAHE
	x Southern Hills
* as reported by ATC directors	x Mitchell

apartment complexes. A few of the directors reported long waiting lists and competition with families for Section 8 subsidies. One director stated that the availability of subsidies often determined if a person in one of their facilities could move to an apartment. In a related area, one ATC director explained that his agency leases apartments because people with disabilities do not have the month's deposit or down payment for utilities that is required in renting most places.

Only one ATC director mentioned that housing was both available and accessible. ATC directors were generally unaware of possible financing sources for making homes accessible, although one accurately mentioned community development funds might be a possible resource. One director reported that he believed landlords would not allow places to be modified (although the interviewer explained how this had been accomplished in other states). Several advocates reported that barriers to integration included the lack of accessible and affordable housing as well as the lack of funds to modify existing housing.

Because of the availability of substandard homes and reportedly **no** local safety codes in some areas of the state, people in the DDD and a number of the ATC directors are justifiably concerned that people with developmental disabilities may end up living in unsafe and indecent places, if safeguards are not in place.

The specific housing situation in each region will need to be reviewed in-depth before determining housing strategies for each area. Based on this preliminary information on affordability, one strategy for consideration in some parts of the state should be the use of a housing subsidy. In addition, given problems with accessibility, strategies for financing home modifications should also be pursued. Safeguards must also be in place to insure that people with disabilities are not placed in unsafe physical conditions.

Mortgages and current financial commitments. One of the impediments to the full implementation of a housing/support services approach in South Dakota is the current financial commitment of the ATCs to facilities, most of which were developed in the past five years and can have mortgages as long as 50 years. Table 4 lists a sampling of the current major financial commitments of the providers to residential facilities.

On the positive side, FmHA requires alternative use plans for all facilities. At a later date, these plans could be useful in examining conversion strategies. It is important to note that even monitored apartments (such as those in ATCO's area) could be under FmHA mortgages. The HUD 202 mortgages are much more problematic. However, as one of the ATC directors stated, divesting from HUD 202 can be done with a lot of effort. Sioux Vocational Services, in fact, is in the middle -of a two-year process of having a HUD 202 financed facility transferred from the ARC to the ATC. This long-term issue will require further investigation.

Currently, the major problem is the continued development of apartment buildings for the sole use of people with developmental disabilities through HUD. Specifically, developments in process include a 12-bed supervised apartment building by the Yankton ATC, a 14-bed supervised apartment building in Chamberlain, two 12-bed apartment buildings by Black Hills, and one supervised apartment building by Sioux Vocational Services. In addition, UCP of South Dakota is in the process of rebuilding one of its homes. By contrast, several of the smaller ATCs mentioned

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TABLE 4
Sampling of Mortgage Commitments for Residential Facilities

FmHA	Conventional	HUD
Yankton (3 CRF)	Winner (2 CRF)	Chamberlain (3 CRF)
ATCO (all)	UCP (2 CRF)	Southern Hills (1 CRF)
Brookings (1 CRF)		Sioux Falls (7 CRF)
Mitchell (4 CRF)		Black Hills (5 CRF)
Winner (1)		Live Ctr. (1 CRF)

Other or Source Not Reported

Aberdeen (2)	Black Hills (4 leased with restrictions)
Sioux (2)	OAHE and Brookings (SBA loans)
Huron (all)	ECCO (4 CRF)

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that they are considering moving from a larger group home to a smaller site or reducing the size of an existing home (e.g., Live Center, Winner).

With few exceptions, the ATC directors said their organizations would consider divesting from their current buildings, if financially feasible to do so. However, most

would be hesitant without first "seeing if the philosophy worked." This is reasonable and prudent at this time given the time commitment for change, people's current understanding and experience with this approach, their need to insure the stability of their organizations and their concern for the well-being of the people they are currently serving.

Several directors mentioned it was standard practice in South Dakota to congregate people with disabilities and it would be difficult for their boards and parents to commit to such a change. A few noted that other groups such as the elderly and people with other disabilities would be very interested in securing the buildings, if they became available. Only one director argued large segregated buildings were "programmatically sound" and another that people could become isolated in "four or six-bed homes." These last two issues have been discussed in Part I of the report.

Home ownership by parents and people with disabilities. Figure 7 lists some of the current housing strategies that can be used to develop small, integrated and affordable housing and/or promote home ownership by parents and people with disabilities. Appendix VII contains a list and description of resources, organizations and programs using these specific approaches.

FIGURE 7
HOUSING STRATEGIES

I. Housing Subsidies
II. Housing and Trusts
III. Housing Associations
IV. Private Cooperatives
V. "Creative" Financing

Most of the ATCs are unfamiliar with these possibilities, which is typical in the disability field at this time throughout the United States. Several ATC directors expressed enthusiasm about the possibilities of home ownership by parents and people with disabilities; for example, "I'd love to see people buy into existing options going up in town."

Long-Term Recommendation 10A: The Division of Developmental Disabilities, in conjunction with other state agencies, should investigate other financing for housing that could support people with severe disabilities in more integrated ways.

As part of this process, the DDD and the ATCs will need to become at least generally familiar with housing issues in their state/region. On a short-term basis, the focus should be on finding alternatives to building new facilities and on seeking other housing alternatives as feasible to do so. Although discussions should take place regarding future uses for existing facilities, DDD should at this point focus on new developments as opposed to conversions. As mentioned earlier, while the ATCs and DDD must become familiar with the housing situations, they should not directly purchase or build additional homes. This statement, however, should not be interpreted as relieving these organizations from their responsibilities for assisting people with developmental disabilities to live in decent and safe homes. It simply means that the role they play in regard to housing will need to change.

10A(1): The Division of Developmental Disabilities should review the housing supplement established by the Connecticut Department of Mental Retardation and North Dakota Department of Developmental Disabilities as one method for making housing affordable to people with disabilities.

When housing is available, but not affordable and when people with disabilities do not have funds for initial rent and utility costs, one option to consider is a housing subsidy. Appendix VII describes several subsidies currently in operation in other states and funded through developmental disabilities services. Housing subsidies can be an effective and economical approach to housing for some people with disabilities. The ATC directors and the DDD should also become more familiar with the use of Section 8 housing subsidies for typical, integrated and decent housing. While waiting lists are an issue in every state, an awareness of the importance of this individual subsidy for people with developmental disabilities is important in influencing future availability of housing subsidies on the federal level.

10A(2): The Division of Developmental Disabilities could explore the development of a demonstration effort on generic private cooperatives as one alternative to continued development of segregated apartment buildings.

Given the tremendous interest in the state in the concept of supervised apartments, one viable alternative for new development could be a cooperative (for people with and without disabilities) developed through a housing association. Several of the ATCs have the capacity to work with housing groups to develop what could be a model effort in the country. Such cooperatives are being pursued in states such as New Hampshire and Connecticut, as noted in Appendix VII. In conjunction with the cooperative, the DDD should work with the ATCs to provide individual supports to each person with a disability involved with the project.

10A(3): South Dakota should explore the establishment of a housing trust fund with an emphasis on integrated housing options.

This recommendation may best be pursued by a broader group that includes parents, advocates, and people with disabilities as well as representatives of key organizations in the state. The Illinois group will provide consultation to states interested in pursuing this approach. Appendix VII describes a number of different trust funds and South Dakota will need to examine which strategies best meet needs in this state.

10A(4): At least one region, where local housing is not available, should examine the establishment of a "creative financing" project using private investors and low-income tax credits.

This project should be developed in a region where local housing is not available or where creative financing could be used for existing homes. In South Dakota, this project could be an example of a fiscally viable way of expanding available housing, of promoting small, integrated housing, and fostering the separation of the housing and support services roles. This type of project requires assistance through people skilled in real estate and housing financing. While the ATCs may be a co-sponsor of an initial project, in the long term, the DDD and the ATCs should focus their efforts on the support service aspects and develop local capacities through generic housing groups.

10A(5): The Division of Developmental Disabilities, in conjunction with the Adjustment Training Centers, should investigate funding for physical accessibility modifications of typical homes and apartments.

Only a few of the individuals we interviewed were aware of the status of funding for accessibility modifications in the state. Many states include funding for home modifications under the HCBS waiver; community development funds are often used for items such as ramps for homes; independent living funds through vocational

rehabilitation are another resource. Other places have developed cooperative strategies where one organization pays for the materials for the modifications and another provides the necessary labor. In addition to the financing, several states have found that developing the capacity to modify homes for specific individuals may also take time and experience.

Recommendation 10B: The South Dakota Division of Developmental Disabilities, in conjunction with housing agencies and organizations, should insure the use of decent and safe housing alternatives for people with developmental disabilities.

The Division should require quality of life standards (see Appendix V), including housing standards, to guide agencies that assist people with developmental disabilities to locate housing. As mentioned previously, the DDD should promote the use of safe and decent housing through the implementation of the framework mentioned in Part I of this report. DDD should require certification of any apartment/home owned or leased by an agency, including monitored apartments. People's own homes or apartments (including monitored apartments) should not be certified, although the quality of life standards should apply.

The general direction should be for all organizations, no matter what population group they support, to work toward safe and decent housing for South Dakota's citizens. As the Black Hills director stated, "We dehumanize the handicapped by expecting what none of us has. For people in their own homes, the same things should be in place as anyone living in their own place." When local codes exist, they should be applied to people with developmental disabilities living in homes they rent or own. When no codes exist, the quality of life standards on housing should apply to how an agency supports the individual in selecting housing.

Issue 11: Individual Assessment, Planning and Funding

All significant decisions must be based on and/or made by the person with a disability with support from the significant people in the person's life. Thus a close tie must exist among assessment, planning and funding. This is a substantial departure from the typical residential development process where most of the significant decisions on housing and services (e.g., the size of the arrangement, the number of staff, the level of supervision, the selection of the site, the level of disability and the operating budget) are made prior to the involvement of the person with a disability. The concept of individualized funding is a key component of this process.

The current process of services planning, assessment and funding used by the ATCs represents the traditional framework. Figure 8 compares and contrasts the traditional process of decision-making for the development of residential services with the decision-making process in a more individualized approach.

Assessment. The ATCs rely almost exclusively on standard deficit-based assessments both prior to and upon entrance to residential services. The Minnesota inventory is used to determine waiver eligibility and the ICAP is reportedly mandated by DDD for planning. One organization used at least eight different assessments, also noting they had additional assessment tools available. Many of the ATCs have developed and/or modified assessment tools for their use.

A number of ATCs also used a more informal process of "getting to know the person" although this occurred after the individual was admitted into the residential program. As one director said, "For the most part, it's based on what the staff know about the person; also family opinions about this. It is individualized, not based on a score or number of hours...We rely on staff dedication and observation."

As mentioned earlier, increasingly organizations are moving from a reliance on deficit-based assessments to more community and individually-based processes of getting to know an individual with his/her unique strengths and dreams. This represents a major change from the heavy skill and problem focus of traditional assessment strategies.

FIGURE 8
Sample Decision-Making Process

Facility-Based	**Person-Centered**
1. Community needs assessment	1. Assessment of individual's support and housing needs
2. Population -Level of disability -General supervision level (24 hr. or less than 24 hr.)	2. Development of housing and support plan 3. Selection of support providers
3. Type of facility -Size of facility -Accessibility, special requirements	4. Selection of roommates (if any) 5. Selection of specific home or apartment
4. Agency sponsorship	
5. Fiscal negotiations for facility -Capital, start up, operating	6. Negotiation of individual's funding
6. Specific site selection	
then	
7. Selection of specific people who meet eligibility requirements of facility	

Assessments in South Dakota are used to determine eligibility for services, to determine when a person is ready to move or have greater freedom, and to pinpoint what areas of training a person will need within the facility. In contrast, new approaches

to assessment create a picture of the uniqueness of the person "in order to determine what forms of help the community needs to plan, arrange, provide and monitor services to meet his/her needs" (Brost, et al., 1984).

Services planning. In South Dakota, the individual services planning process typically follows the traditional approach of matching people with available facilities and services. Several ATCs, however, did have a process that tried to address people's needs beyond what was currently available and these organizations should be encouraged and supported in their efforts.

The individual habilitation plan (IHP) is developed within 30 days of placement by the interdisciplinary team. The interdisciplinary teams, while varying across the state, generally are dominated by ATC staff. It appears that participation by the person with a disability and family members on the interdisciplinary teams is a regular practice at the ATCs. Advocates, however, expressed some concerns about the access of advocates to these meetings in some parts of the state. In contrast, places such as Huron ATC explicitly state in their policies that the client's advocate should be present.

Parents and people with disabilities are not, however, standardly involved in team meetings prior to the determination of the residential site at the ATC. Admissions committees often involve only staff of the program with no representation by parents, people with disabilities or other community members.

On the positive side, a number of directors stressed that the individual habilitation plan (IHP) was based not only on assessments but on "what the client and family feel they need." This is a step toward person or family-determined supports and services. At the same time, several people with disabilities felt the purpose of these meetings was primarily for the benefit of staff. Though the people with disabilities

participated in the process, the meetings did not address the issues they saw as relevant in their own lives.

A number of the ATC staff have been exposed to the process of personal futures planning (O'Brien, 1987), which has been used successfully in other places to help create a shared vision of the valued possibilities in the lives of each individual. In particular, this process can help people confront the fact that not all issues can or should be addressed through services. It also changes the fundamental question from "how does the person need to change?" to "what can we all do to support these positive things to happen in the person's life?" In moving to an individualized approach, such a process could be useful to expand the possibilities for support pursued in the person's life. There does seem to be some confusion, however, in South Dakota, on the differences between this process and the traditional IHP.

In developing the service plans, several ATCs mentioned that they first try to use community resources and provide services only if these are not available. We concur with this basic approach, although agencies may also provide support services to community agencies as opposed to developing new human service agency programs. One ATC only used community resources when the human service agency was not able to provide the necessary services (a fundamental reversal of the normalization principle). This is extremely problematic since it makes the agency and special services the focus of the lives of people with disabilities.

Funding. Compared to most funding schemas, South Dakota does have more flexibility and capacity to be individualized. There are, however, a number of problems with the current design of the financial system to support community living. From the perspective of the individual, the primary issues include: (1) the use of a "slot allocation" system; (2) standard payment rates for people with severe disabilities and for

individuals with less severe disabilities within a given funding source; (3) inability to combine the home and community-based Medicaid waiver with funding sources such as foster care and state general funds; (4) no mechanisms outside the agency for responding to emergencies, such as possible reinstitutionalization; and (5) limitations, including those imposed by the state, on the use of funding.

The following is a brief description of each of these issues:

First, when "slots" are allocated to private agencies, several problems occur. These include: (1) a tendency to find individuals to fill those "slots," thus encouraging the use of the service system as opposed to more informal supports; (2) inequities in the distribution of services, since people with great need may not be in a region with adequate "slots," while other people may have unfilled "slots"; (3) difficulty in planning for individuals since the priority is to fill the "slot" versus meet the needs of the individual; (4) encouragement of displacement from one's home community, since an individual may need to move to another region unless the other ATC agrees to give up "their slot"; and (5) disjointedness between the assessment, planning and funding processes, since a funding "slot" is the same for every individual no matter what their service needs.

Second, if an individual is eligible for a certain funding source (e.g., HCBS), the "slot" allocation amount is the same no matter what the severity of the person's needs or the other resources currently available to them. This approach tends to encourage providers to serve people with the mildest disabilities as opposed to people with more challenging needs. The DDD has stated that the provider is not restricted from averaging the funding across people (within a specific category such as HCBS). However, in practice, this occurs only within a limited range and only in relationship to facilities/programs. In other words, as described previously, the current funding allows

the provider flexibility, but does not in turn give flexibility to individuals. There is also no mechanism for providers to obtain additional funding if the standard rate is inadequate (even if averaged across people) for an individual.

Third, experience in a number of states indicates that one strategy for initially financing individualized supports for adults is to use a variety of existing funding sources in combination to meet the needs of individuals. This recommendation, however, does not apply to ICF-MR funding since there are strict federal limitations on combining this funding with other resources. As discussed previously, except for ICF-MR funding, DDD policies should not restrict the combining of funding sources (e.g., foster care, followalong, CLT, and HCBS) in support of the same individual. Removing such restrictions, however, should be done as part of a broader financial planning process by DDD.

Fourth, as mentioned earlier, the DDD may want to establish a mechanism such as the temporary services supplement in Connecticut or the exceptions payment mechanism in Michigan to insure that reinstitutionalizations do not occur.

Fifth, the current system places a number of limitations on the use of funding, including the types of services fundable, and the locations where funding can be used. In moving to a more individualized approach, these restrictions (often reflected in definitions of services and funding categories) will need to be revised.

Recommendation 11A: South Dakota should develop a process to revise its assessment, planning and funding processes to be more individually-based.

South Dakota should examine the individual service assessment, planning and funding processes used in such states as Wisconsin, North Dakota, Colorado, and Minnesota under each state's home and community-based Medicaid waiver (see Appendix VI). In each of these systems, the process starts with getting to know the

person as an individual, whether the person is living in the community or in an institution. A housing and support plan then is developed for the specific person, including the cost of services and potential funding source(s) for each service. In this way, the person's needs are examined first, services are then developed and the funding sources can be "mixed and matched" to meet those individual needs. In Minnesota and Wisconsin, counties are responsible for maintaining their average under the waiver, but they can fund one person at a lower rate and another at a higher rate depending upon individual needs. In Minnesota, a Special Commissioner's fund was used for people with severe disabilities whose service needs greatly exceeded the average allocation amount. North Dakota's system includes an individually-negotiated rate and can also include a housing subsidy if needed. The North Dakota and Colorado systems have a closer tie between the individual's housing and support needs and the funding for the individual.

In South Dakota, some people in fact do receive more services and some people fewer services for the same funding amount. Thus, providers already average costs across people. Some of the major differences between South Dakota and the other states mentioned above include: (1) in South Dakota the funding is determined first, then the placement and then how the individual needs can be met; (2) different types of funding are often combined in other states to meet individual needs; (3) in each of those states, there is an organization outside the provider responsible for developing and/or reviewing the individual support and housing plans; and (4) efforts in other states have focused on an "individualized" as opposed to a "facility-based" approach to supporting and funding adults in the community.

Initially, the DDD should move to a services assessment, planning and funding process similar to those in Wisconsin or Minnesota; an individual-negotiated rate process

can be developed once the regional support structure with adequate staff are in place (see Recommendation 1A).

Recommendation 11B: South Dakota should examine combining foster care payments together with DDD funds to support adults in their own homes (as opposed to the traditional foster care model).

Many states have found that foster care for adults can be one of the resources in moving to an individualized approach. Most foster care regulations, for example, do not prohibit two people (one of whom is disabled) from together locating a home or for the person with a disability to select with whom he/she would like to share a home. Regulations also typically assume, but do not require, that the foster care workers function as parental models. Approaches where roommates, one with a disability and one without, share a home are also possible. A review of South Dakota's regulations (chapter 67:42:02) indicates that this is probably also the case in South Dakota.

In an individualized approach, foster care is viewed not as a traditional family care program, but as an existing mechanism that may be modified to provide additional fiscal resources (e.g., the current supplemental payment) and possible oversight. Since supplemental payments are relatively small, the fiscal advantages to this approach are not as great in South Dakota as in some states.

Since South Dakota does not have a specialized system of foster care for people with developmental disabilities, this would require an agreement and new relationship with the Department of Social Services. As mentioned previously, for some individuals, Medicaid waiver funds should also be available to support the individual living with a roommate and/or with a more traditional foster family.

Issue 12: Consumer-directedness of Services/Housing

An individualized approach promotes increased choices in major and minor life areas by people with disabilities, including where and with whom people live. In many ways, it represents the fundamental premises of the independent living movement applied to people with severe developmental disabilities. One of the critical aspects of an individualized approach is the increased choice a person with a disability has over the services and housing that impact upon his/her life. It is possible, however, to implement all other aspects of an individualized approach without addressing this essential aspect. This approach, if well-implemented, shifts decision-making from the agency to the individuals with disabilities and the significant people in their lives. The recommendations regarding self-advocacy, parent leadership and family-determined support demonstrations contained in Part I are ways of building a foundation for these more fundamental changes.

Recommendation 12A: The Division of Developmental Disabilities (1) should explore its role in encouraging home ownership and leasing by people with disabilities and (2) should examine its policies, procedures and staff training to promote more control by people with disabilities in their home environment.

Promoting home ownership is important because people with disabilities have been systematically excluded as a group from this option. While not all people will lease or own homes (either directly or by others on their behalf), the current system in South Dakota and other places denies people (for whom this may matter) this option. Since home ownership has not been explored in South Dakota, policy barriers may exist in the state on the issue of home ownership and leasing by people with disabilities. These could include direct restrictions based on the capacity of individuals or effects on

other benefits and supports based on home ownership. The initial step is to explore the implications and barriers to home ownership within the state.

In addition, when the home is not that of the provider, but of the person, it is more likely that the essential aspects of home--a place where the person has control over his/her environment, a place where the person is comfortable, a place that belongs to him/her--can be achieved. Whether the home is technically owned or leased by the person is less relevant than if the place is, in fact, his/her home. Home ownership, however, is one way of legally shifting the decision-making power in this important area. Even in current facilities, though, agencies can examine their policies, procedures and staff training regarding issues of choice and self-determination. As one example, instead of policies regarding home visits, adults should be supported in making their own decisions on these issues, in conjunction with their families. As many of the ATCs have done, people can at least be involved in selecting their own roommate.

Recommendation 12B: The Division of Developmental Disabilities should promote greater participation by people with disabilities in planning and decision-making.

12B(1): All ATCs should be encouraged to involve people with disabilities in selecting staff and in participating in boards and committees.

The ATCs could encourage greater participation by people with disabilities in areas such as the selection of staff. In some places (e.g., Options for Community Living), people with disabilities are being supported to hire, fire and manage their own staff. In other places (e.g., Minnesota), agencies may hire staff to work directly with a specific person as opposed to the agency as a whole. Still other places (e.g., Shoultz, 1989), try to match people with disabilities and staff based on their existing or potential for a good relationship. In facility-based services, potential staff may be interviewed by

the people living in the home who give their input to the people doing the hiring. All of these strategies could be explored by the ATCs.

Adults with disabilities, just like other adults, do not always hold the same opinions and desires as their parents. The ATCs should seek advice not only from parents, but from people with disabilities as well. Region V, Nebraska has a resident advisory group that has functioned effectively for many years. Some of the ATCs may want to invite Nancy Ward, a staff member of People First in Nebraska who helped to form and support the resident advisory group, to South Dakota.

12B(2): The Division of Developmental Disabilities, in conjunction with other organizations, should develop opportunities for staff to discuss issues of risk, autonomy and self-determination.

This recommendation builds on the Part I recommendations on self-advocacy, but focuses on service providers. As part of the process of developing the supportive living demonstrations, providers will need opportunities to talk with other service providers who have worked out concerns regarding agency liability and individual autonomy. In working with states, we have found that most places had no more liability than would occur with any new program or endeavor. In addition, people built in safeguards by continuing to use a team approach for making decisions. Additional supports might be developed at the beginning partially for the security of team members. Parents at times have spent the first few days in the home until they felt secure and trusted the staff. The major theme is the importance of building an atmosphere of collaboration among all team members and at the same time remembering whose life it is (i.e., the person with a disability).

Recommendation 12C: Demonstration projects should include a consumer-directed approach to services and housing.

This aspect of a supportive living approach should be explicitly included as part of the long-term demonstrations in the state. There is an independent living center in the state and a joint project between one of the ATCs and the ILC could be considered. While the ILC in South Dakota, as in most states, is oriented primarily toward people with physical disabilities, typically the ILCs have a strong philosophy and orientation toward consumer-directedness of services. Their input may be important in insuring that the new approach does not remain solely provider-driven.

SUMMARY

This report has described a number of different areas that can be pursued by the Division of Developmental Disabilities to improve the lives of adults with developmental disabilities in South Dakota. Part I examined important issues facing the service system, whether or not major changes are sought. Part II discussed how South Dakota can examine its services and begin playing a leadership role in the field of developmental disabilities.

In Part II, the major issues and recommendations in implementing a housing/support approach can be described by the following themes:

(1) breaking down existing barriers in the current system to allow support services to be provided in people's own homes,

(2) developing experience and examples around the state in what it means to support people with more severe disabilities individually and flexibly in the community,

(3) working with new agencies and organizations to explore other opportunities for housing and support financing,

(4) developing an "individualized" approach initially for a targeted group of people in the state,

(5) working toward the long-term changes necessary for the more major systemic redesign of residential services in the state.

South Dakota has an opportunity to build on its current community services and to move forward into the 1990s further promoting the full and meaningful participation of people with disabilities in community life.

REFERENCES

Braddock, D., & Heller, T. (Eds.). (1984). The closure of state mental retardation institutions: Proceedings of a conference of the National Association of State Mental Retardation Program Directors. Alexandria, VA and Chicago, IL: National Association of State Mental Retaration Program Directors and the Institute for the Study of Developmental Disabilities.

Brost, M. M. & Johnson, T. Z. (1984). Getting to know you: One approach to service assessment and planning for individuals with disabilities. Madison, WI: DHSS-DCS.

Johnson, T. Z. (1985). Belonging to the community. Madison, WI: Options in Community Living.

Knoll, J., & Ford, A. (1987). Beyond caregiving: A reconceptualization of the role of the residential services provider. In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities (pp. 129-146). New York: Teachers College Press.

Lakin, C. (1988). An overview of the concept and research on community living. Minnesota: Research and Training Center on Community Living, University of Minnesota.

Leadership Institute. (1989). From Being in the Community to Being Part of the Community. Syracuse, NY: Center on Human Policy, Syracuse University.

Lippert, T. (1987). The case management team: Building community connections. St. Paul, MN: Developmental Disabilities Program of the Metropolitan Council.

Lord, J., & Hearn, C. (1987). The process of closing an institution. Ontario: Centre of Research and Education in Human Services.

Maynard, C., Wratz, J., & Beckwith, H. (1989, January). Report of the South Dakota Autism Task Force. South Dakota: Author.

O'Brien, J. (1987). A guide to life-style planning: Using the activities catalog to integrate services and natural support systems. In B. Wilcox and G. T. Bellamy, A comprehensive guide to the activities catalog: An alternative curriculum for youth and adults with severe disabilities. Baltimore, MD: Paul H. Brookes.

O'Brien, J., & Lyle, C. (1988). Framework for accomplishment: A workshop for people developing better services. Decatur, GA: Responsive Systems Associates, Inc.

O'Brien, J., & Lyle, C. (1986). Strengthening the system: Improving Louisiana's community residential services for people with developmental disabilities. Decatur, GA: Responsive Systems Associates, Inc.

Racino, J. (in press). Community living: Issues in personnel preparation for the 1990s. In A. Kaiser & C. McWhorter (Eds.), Preparing personnel to work with persons who are severely handicapped. Baltimore, MD: Paul H. Brookes.

Racino, J. (1989). Community living for adults in North Dakota: A case study of an apartment program. Syracuse, NY: Center on Human Policy, Syracuse University.

Racino, J. (1988). Individualized family supports and community living for adults: A case study of a for-profit agency in Minnesota. Syracuse, NY: Center on Human Policy, Syracuse University.

Racino, J., & Merrill, D. (1989). Residential supports for children with severe disabilities in Northeast South Dakota. Syracuse, NY: Center on Human Policy.

Shoultz, B. (1989). Regenerating a community: The story of Residential, Inc. in New Lexington, Ohio. Syracuse, NY: Center on Human Policy, Syracuse University.

Smith, G. A., & Alderman, S. (1987). Paying for community services. Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc.

Smith, G., & Gettings, R. (1988). An assessment of services to South Dakota's citizens with developmental disabilities. Virginia: National Association of State Mental Retardation Program Directors.

Taylor, S. J. (1988). Caught in the continuum: A critical analysis of the principle of the least restrictive environment. Journal of The Association for Persons with Severe Handicaps, 13(1), 41-53.

Taylor, S. J. (1987). Community living in three Wisconsin counties. Syracuse, NY: Center on Human Policy, Syracuse University.

Taylor, S. J. (1985). Report on the Macomb-Oakland Regional Center, Michigan. Syracuse, NY: Center on Human Policy, Syracuse University.

Taylor, S. J., & Racino, J. A. (1987, November). The clustered apartment model of services. TASH Newsletter, 13(11), 8.

Taylor, S. J., Racino, J. A., Knoll, J. A., & Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with the most severe disabilities. Syracuse, NY: Human Policy Press.

Taylor, S. J., Racino, J. A., & Rothenberg, K. (1988). A policy analysis of private community living arrangements in Connecticut. Syracuse, NY: Center on Human Policy, Syracuse University.

Walker, P., & Salon, R. (1987). Report on Centennial Developmental Services, Inc., Weld County, Colorado. Syracuse, NY: Center on Human Policy, Syracuse University.

Wolfensberger, W., & Thomas, S. (1983). PASSING: Program Analysis for service systems' implementation of normalization goals. Canada: National Institute on Mental Retardation.

Zirpoli, T. J., Hancox, D., Wieck, C., & Skarnulis, E. (1989). Partners in policymaking: Empowering people. Journal of The Association for Persons with Severe Handicaps, 14(2), 163-167.

APPENDIX I

CENTER ON HUMAN POLICY

Individualization and flexibility in community living arrangements

by Steve Taylor, Julie Racino and Kathy Rothenberg

Individualization and flexibility are two important aspects of community living for people with disabilities. Individualization occurs in community living when priority is given to a person's preferences about his or her living conditions (such as where and with whom he or she might live). Flexibility means adapting services and supports as a person's life situation changes. Most states, however, do not consider individualization or flexibility when planning residential programs. It is common practice for states to create a residential program (e.g. group home) for a given number of "clients," select "appropriate" people to live in the home or apartment and, finally, attempt to modify the program to meet the individual needs of the people living there.

In this article we contrast the facility-based approach to community living (i.e., the traditional approach of group home and supervised apartment development) with the non-facility- based, individualized or person-centered approach (i.e., that which begins with the needs of the person first). We also suggest areas to consider when designing guidelines for individualized supports, including the tie between individual planning and funding, the payment of housing costs and other expenses, a range of housing options, the provision of flexible supports, licensing and quality assurance and incentives for providers.

Characteristics of a facility-based approach

Most states adopt a facility-based approach to community living, centering on the program or facility rather than the needs of the individuals who live there. Such an approach allows for only a limited amount of flexibility and/or individualization.

A facility-based program typically incorporates the following elements.

Licensing of facilities. Private community living arrangements are licensed facilities. Although licensing is appropriate, it often tends, by its nature, to limit people's choices and where and with whom they will live.

Agency owned or rented. Private community living arrangements are agency operated, owned or rented facilities. Since providers own or rent the residential setting, they ultimately control who lives there. Under this arrangement, "the person with a disability is a guest in someone else's home." O'Brien and Lyle (1986).

Agency staffed. Private community living arrangements are staffed by people hired, paid and supervised by the agency operating the facility. Staff are employed by and accountable to the agency, rather than the people receiving the services. The staff's relationship with people is defined by the conditions of employment created by the agency and staff.

Staffing ratios based on the group, not the individual. Staffing ratios and levels of supervision are based on the needs of the group of people living at the facility.

As a general rule, people in the group receive the level of supervision required by the person with the most intensive needs. To the extent that an individual has more or less intensive needs than others, he or she may not "fit into the program."

Linkage of housing and support. In order to receive services from a provider, people must live at the provider's facility; providers are reimbursed only for services provided to people living in their facility.

Core funding tied to the facility, not the individual. Funding is based on the needs of the facility rather than the individuals. This funding does not allow for or extend to a person's transition into his or her own home.

Weak relationship between individual planning and funding. There is a weak relationship between planning for an individual's needs and funding for community living arrangements; the rate-setting and the planning process proceed relatively independently.

Characteristics of a Nonfacility-based or individualized approach

The emphasis we make on the distinction between a facility-based approach and an individualized approach to community-based support services is similar to that between a "Landlord Strategy" and "Housing Agent/Personal Support Strategy." (O'Brien and Lyle 1986). As O'Brien and Lyle point out, although a Housing Agent/ Personal Support Strategy would open the way to more effective services, funding and regulatory barriers can stand in the way of adopting this approach. For a summary of select key elements of an individualized approach to community support for people with developmental disabilities, see "Supporting Adults With Disabilities in Individualized Ways in the Community," in the March 1988 *Newsletter* .

The central feature of a nonfacility-based, or individualized approach is the *separation of housing and support*. . A manual prepared by Options in Community Living, a community support agency in Madison, Wisconsin, describes why it is important to separate housing from support:

"....One agency should not provide both housing and support services. While we often advise and assist clients in finding, renting and furnishing their apartments,

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Options no longer becomes the leaseholder or the landlord for client apartments. We want our clients to feel both control over and responsibility for their own living spaces. We also believe that receiving Options' services should not affect where clients live; our clients have a greater choice of living situations and know that beginning, ending or changing their relationships with us will not put them under any pressure to move. This policy also frees us from the time-consuming responsibilities and sometimes conflicting relationships involved in being a landlord." (Johnson, 1986).

Housing arrangements. Under a nonfacility-based approach to community support, adults should have access to a range of housing options. While housing should be separate from support services, an agency might assist people in locating housing, signing leases, negotiating with landlords, matching roommates, purchasing furniture and furnishings, arranging for architectural adaptations and obtaining housing subsidies. There are several kinds of housing arrangements available.

1. Own home. This includes housing owned or rented in the person's own name. In most states, people with disabilities receive little, if any, support if they reside in their own homes.

2. Parent's or guardian's home. This refers to housing bought or rented by the parent or guardian on behalf of a person, but not occupied by the parent or guardian. Families caring for members with mental retardation should have access to an array of supports, these supports typically fall under the category of "family supports" as opposed to community residential supports.

3. Shared home. This refers to a home jointly owned or rented by two or more persons, one or more of whom has a developmental disability. As in the case of any joint living arrangement (e.g., a married couple, college roommates), all parties are equally entitled to live in the home. Housekeeping, finances and other living conditions would be open to negotiation.

4. Existing home and household. This includes an existing home into which one or more people with disabilities move. The traditional foster home is an example of an existing home and household. As in the case of an agency facility the person remains a guest in someone else's home.

5. Cooperative. In a cooperative a person joins in the ownership of housing as a member of an entity.

6. Corporation owned or rented. For people lacking the legal capacity to own or rent property and who do not have parents or guardians, corporate ownership or rental of housing may be necessary. Since housing should ideally be separated from support services, the corporation owning or renting the housing should be separate from the one providing services.

Paid support. A variety of supports and services should be accessible to people, regardless of where they live. The following are strategies for providing support, supervision or services to people with disabilities. Note that these strategies are limited to paid support.

1. Agency staffing. Agency staff can provide both direct and indirect support to people. In addition to staff providing direct services, some agencies which support people who live in their own homes employ community resource staff who provide individual service coordination, assist in the management of attendants, provide training and offer back-up services.

a. Live-in staff. This includes agency employees who live with people with disabilities.

b. On-call staff. This refers to agency employees who are available for on-call services to people. On-call staff may live near people supported by an agency and be accessible through emergency communication systems. A live-in staff person at one home may be on-call to assist people in another.

c. Other staff. Other kinds of agency staffing include "drop-in" staff and staff who work specified hours.

2. Non agency staffing.

a. Paid roommates or companions. Paid roommates or companions are people paid to live with and provide support to people with disabilities. A paid roommate could be a family provider who accepts a person into his or her home or someone recruited to provide support to a person in a shared living arrangement or a person's own home. In contrast to agency staff, a paid roommate is considered self-employed. Ideally, the person with a developmental disability participates in the hiring and supervision of the paid roommate.

b. Paid neighbor. This can be a person from the neighborhood or apartment complex paid to provide assistance to a person with a developmental disability or to be on-call in case of emergency. Like a paid roommate, a paid neighbor could be self-employed.

c. Attendant. We use this term to refer to someone who is employed directly by the person with a disability. While attendant care has been commonly thought of as an option for people with physical disabilities, this approach has recently been used to support people with mental retardation and severe disabilities. Funding for attendants can be provided directly through public agencies or through private agencies contracted to administer attendant care funds.

Individualization and flexibility. Theoretically any individualized housing arrangements can be matched with any one or more types of individualized support. For example, a person with mental retardation living in his or her own apartment or a house owned by a parent can be supported by one or any combination of live-in agency employees, on-call agency employees, drop-in agency employees, paid roommates, etc.

While no state has yet fully implemented an individualized, nonfacility-based or person-centered approach to community living as described in this article, some have put flexible funding into place. This funding includes creative uses of federal funds such as the Medicaid waiver, which permits the development of more individualized community supports. In addition, this non- facility based approach has been pioneered by several agencies—notably Options in Wisconsin and Centennial Developmental Services in Weld County, Colorado—which have patched together state and county funding mechanisms.

Guidelines for individualized supports. Since most states and providers have operated within the confines of more rigidly defined community living arrangement programs in the past, it may be important to develop guidelines to assist providers with offering individualized services. One way to develop guidelines is to convene a statewide or regional work group, including such members as state officials, regional and/or county officials, private providers and parent and consumer representatives.

The following are some major issues which might be addressed in such guidelines.

1. Tie of individual planning and funding. In a nonfacility- based approach, there is a close relationship between individual planning and funding. The "cost center" should be the individual, not a facility or agency. Steps in individualized rate-setting might include: (1) individual needs assessment; (2) developing an individual plan; (3) determination of housing costs (see the discussion below), direct support costs, additional staffing costs (e.g., coordination, relief, assistance in attendant management, recruitment of paid roommates or attendants), agency costs; (4) review of costs in light of available resources; (5) determining an individual rate.

2. The payment of housing costs and other household expenses. A housing subsidy program is one way of assisting people with disabilities to live in their own homes. Since Section Eight funds are extremely limited in most states and waiting lists are extensive, at least one state has established a subsidy program that can assist people who are not currently receiving Section Eight funds to pay housing costs in their own homes. Like the federal Section Eight housing subsidy, this subsidy pays the difference between 30 percent of a person's net income and the total housing and utility costs up to a specified maximum.

In addition to assistance in meeting housing costs, some people will require financial assistance to pay for furniture, phone systems and communications devices, furnishings and household expenses. People should have the opportunity to own their furniture and household goods. A grant or loan program might be established to assist people in meeting these expense.

3. A range of housing options. Listed under the housing options we have identified are cooperatives and housing owned or rented by a corporation on behalf of an individual. The use of these options may require creative financing approaches and legal assistance. In addition, recognizing that accessibility standards for individual homes must vary from those for facilities, there may be a need for consultation on making cost-effective renovations to existing housing and financing adaptations.

4. The provision of flexible supports. Since providers often rely exclusively on agency staff, including shift staff, they may require guidance on providing flexible and individualized supports to people through live-in and on-call staff, paid roommates, neighborhood support workers and attendants. The Options manual, *Belonging to the Community* (Johnson, 1986), is an excellent resource on flexible supports for people with disabilities. In addition to staff support, emergency on-call systems, adaptive equipment and other service or cash support will also need to be explored.

5. Licensing and quality assurance. Supporting people in a range of housing options, including their own homes, raises serious questions for licensing and quality assurance. While agency operated facilities and existing homes should be licensed, it is restrictive and intrusive to require people to live in licensed facilities as a condition of receiving services. Yet at the same time, it is reasonable to expect minimal safeguards to be in place. The state might consider licensing agencies or support personnel rather than physical facilities. They can also require agencies to conduct reviews of the quality-of-life of the people they support. Options has developed a thorough quality- of-life review for the people it supports in the community (see Johnson, 1986).

6. Incentives to providers. As with any new approach, the development of individualized supports may require major efforts on the part of existing providers. In order to encourage providers to develop new supports or convert existing services, states might fund modest ($5,000 to $10,000) (planning and development grants for providers. These grants might be used to fund visits to agencies in other parts of the country, to train staff or to obtain consultation.

These areas are not designed to be comprehensive guidelines for individualized supports, but are suggested as a starting point for places that are beginning to examine a more individualized approach to community living.

Conclusion

It is important to note that the above discussion applies to the development of community living arrangements for adults. Children with the most severe disabilities are being supported today in birth, adoptive or foster families. As part of our ongoing work on community living for adults, we have presented some important components of a non-facility-based approach to services. This article is designed to assist people in states and local communities to examine their current residential programs and move toward more individualized approaches to supporting adults with severe disabilities in the community.

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References

Johnson, T.Z. (1986). *Belonging to the community*. Madison, Wisconsin: Options in Community Living and the Wisconsin Council on Developmental Disabilities.

Johnson, T. & O'Brien, J. (1987). *Carrying Options story forward: Final report of an assessment of Options in Community Living.*

O'Brien, J. & Lyle, C. (1986). *Strengthening the system: Improving Louisiana's community residential services for people with developmental disabilities.* Decatur, GA.: Responsive System Associates.

Racino, J.A. (1988, March). Supporting adults in individualized ways in the community. *TASH Newsletter*, pp 4, 5, 7.

Taylor, Steven J. (1986). *Community living in three Wisconsin counties.* Syracuse, N.Y.: Center on Human Policy.

Taylor Steven J., Racino, J.A., Knoll, J., & Lutfiyya, Z. (1987). *The nonrestrictive environment: On community integration for people with the most severe disabilities*. Syracuse, N.Y.: Human Policy Press.

Taylor, J., Racino, J. & Rothenberg, K. (1988). *A policy analysis of private community living arrangements in Connecticut*. Syracuse, N.Y.: Center on Human Policy.

Walker, Pamela M. & Salon, Rebecca. (1987) *Site visit report: Centennial Developmental Services, Inc., Weld County, Colorado*. Syracuse, N.Y.: Center on Human Policy.

Excerpt from: Racino, J. A. (in press). Community living: Issues in personnel preparation for the 1990s. In A. Kaiser & C. McWhorter (Eds.), Preparing personnel to work with persons who are severely handicapped. Baltimore, MD: Paul H. Brookes.

SUPPORTING ADULTS TO LIVE IN THEIR OWN HOMES

All people, regardless of severity of disability, can live in their own home in the community. People should have choice about where and with whom they live, control over their environment and how they spend their time.

Gail Jacob, Director, Options in Community Living

Madison, Wisconsin, 1989

The traditional design of community living arrangements has two primary features. First, the guiding policy for the design of these services is the principle of the least restrictive environment, together with its operationalization as a continuum (e.g., Castellani, 1987). People with the most severe disabilities are typically served at the "most restrictive" end of the continuum and those with the mildest disabilities at the "least restrictive" end. Second, the traditional community living arrangements program is a "facility-based" approach, with the program revolving around the living arrangement, or facility, rather than around individuals. It is thus limited in its flexibility and individualization (Taylor, Racino, & Rothenberg, 1988).

In contrast, a newly emerging approach to supporting adults with developmental disabilities in the community is called a "nonfacility-based," "individualized," "person-centered," or "housing/support service" approach. This approach explicitly rejects the continuum concept and overcomes many of the pitfalls of the traditional

design of residential services (Taylor, 1988). Based on the right of an adult to live in a home in the community with whatever supports are necessary, the key service characteristics of this approach include:

Separation of housing and support services

To increase flexibility and individualization, the housing and support components of "residential services" must be separated. Thus, people with disabilities, whether single or married, can have access to a variety of support services, regardless of where they live (Johnson, 1986; O'Brien and Lyle, 1986; Taylor, Racino, Knoll & Lutfiyya, 1987). While housing should be separate from support services, an agency might assist people in locating housing, signing leases, negotiating with landlords, arranging for architectural adaptations and obtaining subsidies (Taylor, Racino & Rothenberg, 1988).

Home Ownership

Increasingly, home ownership and leasing are becoming an option for people with disabilities and their families (e.g., Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, 1989; Racino, 1989a). Although a variety of strategies exists to enable people with disabilities and/or their families to obtain affordable, accessible and decent homes, their potential remains largely untapped. These strategies include the development of private cooperatives (e.g., Kappel & Witherow, 1986; Co-op Initiatives Project, n.d.), the use of trusts for housing (e.g., Teltsch, 1988), housing subsidies (e.g., Taylor, Racino & Rothenberg, 1988; Racino, 1989b), the purchase of homes through housing associations (e.g., Shoultz, 1989) and the creative use of low income tax credits and other financing for housing (e.g., Laux, 1979; Randolph, Carling & Laux, 1987), among others. New endeavors to promote both home ownership and the development of support services are also appearing through the

concomitant development of a housing association and a residential support agency (Shoultz, 1989), a private cooperative together with circles of support (Mount, personal conversation, 1988) or agency support services (Biklen, 1989) and efforts by parents in conjunction with existing agencies (Center on Human Policy, 1989a).

Individual assessment, planning and funding

All significant decisions must be based on and/or made by the person with a disability with support from the significant people in the individual's life. Thus, a close tie must exist among assessment, planning and funding (Taylor, Racino, & Rothenberg, 1988). This is a substantial departure from the typical residential development process where most of the significant decisions on housing and services (e.g., the size of the arrangement, the selection of the site, the level of disability, the number of staff, the level of supervision and the operating budget) are made prior to the involvement of the person with a disability. The concept of individualized funding is a key component of this process, although conceptual and implementation issues still remain (Smith & Alderman, 1987; Racino, 1989b; Tarman, 1989; Salisbury, 1987).

Flexible and individualized supports

An individualized approach focuses on support strategies as opposed to supervision and an almost total reliance on paid, shift staff (Taylor, Racino & Rothenberg, 1988). These support strategies may include paid support, such as live-in, on-call or drop-in staff employed by an agency and hired specifically to work with the person, paid roommates or companions who may be self-employed, an attendant hired by a person with a disability, or a person who lives in the neighborhood and receives payment for services, among others. Support strategies also can include the use of physical adaptations (e.g., automatic door openers, emergency response systems),

routine modifications (e.g., listening to a tape recorder), and the fostering of unpaid support (e.g., Walker & Salon, 1987).

Consumer-directed services

This approach promotes increased choices in major and minor life areas, including where and with whom people live. It can be a step toward greater control by people with disabilities of their housing and support services (Johnson, 1986; Hibbard et al., 1989). In many ways, it represents the application of the fundamental premises of the independent living movement to people with severe developmental disabilities (DeJong, 1979; Frieden, 1978; Stoddard, 1978). For example, people with disabilities can be supported to select or express preferences on the support staff who will work with them.

While the above describes service directions in community living, critical themes for the 1990s may also include issues that are more fundamental and critical to people's lives than services. These may include the importance of living in "one's own home" and an increased emphasis on the broader context of community (Center on Human Policy, 1989). The emerging service directions are important in that they seem to support, or at least not undermine, these fundamental shifts in how we understand community living.

CENTER ON HUMAN POLICY

Supporting adults with disabilities in individualized ways in the community

by Julie Ann Racino, Center on Human Policy

*This article is based on work on individualized supports conducted by **Steve Taylor, Julie Racino, Bonnie Shoultz, Pam Walker, Zana Lutfiyya and Jim Knoll.***

During the past few years, the Center on Human Policy has studied a growing number of places throughout the country where adults with disabilities are being supported in individualized ways in the community. When we first began our national search for exemplary practices in community living in 1985, we expected to identify many good examples of group home and apartment living for adults with severe disabilities. We found that the most exemplary practices represented a new way of thinking about providing supports to people with disabilities. Unlike the traditional approach of establishing residential programs, which fit people into the program and then individualized within the context of the program, these agencies were starting with the person first and developing the supports and housing around the person. This article will describe some of the key elements in this new way of thinking about and developing supports for adults.

Key elements in individualized supports
separation of housing and support components

Probably the most critical element in thinking about and implementing individualized supports for adults is the separation of the components of housing and support services. Typically, we have bundled both together, requiring a person to live in a certain place (e.g., a group home) in order to receive a given intensity and type of support (e.g., 24 hour support). By separating the components of housing and support services, it becomes possible for a person (including a person with severe disabilities) to receive supports wherever he or she may live.

This separation of housing and support services can lead to greater control by the consumers:

• **Choice in Housing** - The person can select from a variety of housing choices, depending on his or her particular circumstances—from a duplex to an apartment, a condominium, a flat, a trailer or a house. The person is not required to live in a certain type of housing in order to receive supports. For example, under the supported independence program in Michigan, a variety of housing options (excluding trailers) are available.

• **Choice of Home Location** - The person can choose where he or she wants to live, including the specific neighborhood. Because the housing and supports are not tied together, the person can have greater choice in the home's location. Thus, the location of the home can build on and strengthen natural supports as opposed to severing those ties. As one staff member in Minnesota said, "we help people to decide what neighborhood they will live in and look for a place that seems right for the people."

• **Choice of Living Alone or With Others** - Because the location and number of people is not predetermined, there is greater flexibility in determining how many people will live together. The option of living alone, at least for a period of time, is an important one for some people. Individualized, however, does not mean that a person will always live alone or with one other person. Someone may also choose to live with a number of other people.

• **Choice of Roommates** - The person can have greater choice in his or her roommate(s), if having a roommate or roommates makes sense in his or her life. By separating the aspects of housing and support services, it becomes easier for a person to choose with whom he or she would like to live. Because supports are not tied to a certain setting, one can live with a variety of people (e.g. "typical" people or family members) or alone and still receive the needed intensity of supports. This approach recognizes the critical importance of the people with whom we live and the impact they may have on our lives.

Housing and home ownership

Central among the many critical issues related to housing, is that of leasing and home ownership. People with disabilities are typically required to move to agency-owned housing to receive intense support services. One of the key elements in an individualized approach for adults is the emphasis on a person's living in a place that he or she owns or leases either alone or in conjunction with others. Only in rare instances should an adult live in the home of another or in agency-owned housing.

Ownership and leasing have both legal and personal ramifications. Ownership means that it is the person's home first and foremost. It is a place where staff, rather than the person, can be asked to leave. People with disabilities have seldom had the opportunity for their homes to be their "castles." This approach underscores the importance of "my home" and the feeling of ownership.

Individualized and Flexible Supports

One of the most critical elements in this type of approach to supporting adults is the individualized and flexible nature of the supports.

• **Individualized Supports** - Unlike the typical approach of fitting a person into existing programs, individualization in this situation means tailoring to or developing the supports that will best match the person and his or her current life circumstances. As stated in the Wisconsin Community Integration Program Medicaid Waiver, "Services must be designed or modified to fit the person and meet that person's unique needs." The individualized nature of the supports is typically accomplished throug-

the establishment of an array of possible supports/services that can be accessed by the person—in any combination. For example, individualized supports can include: dental and medical care not otherwise covered; respite; recreation; homemaker services; transportation; attendant care/home health care; therapeutic and nursing services; home and vehicle modifications; home and community training and support; equipment/supplies; legal services; crisis intervention and counseling services and employment services. Since it is impossible to anticipate every type of support that may be needed, it is very important that the array of services includes another category (or some mechanism to insure that unanticipated needs can be met).

Individualized supports have been provided, to some extent, under the home and community based care Medicaid waivers in a few states. For example, under one state's Medicaid waiver, the following supports can be matched to the individual person and can vary in amount, frequency and duration based on individual needs: respite; homemaker; habilitation (including therapeutic activities; monitoring; supervision; training or assistance in self-care; sensory/motor development; communication; behavioral supports; community living and mobility; health care; leisure and recreation; money management and household chores); adaptive aids and supported employment/day habilitation services. This approach can be more flexibly accomplished through the use of state general funds such as Michigan's supported independence program. Some states combine funding sources (Medicaid, state dollars, county dollars and others) to provide individualized supports.

• **Flexible Supports** - Flexibility means the supports must be able to be adjusted in a timely way both in kind and in intensity. Thus, supports can be changed over time without the person needing to move from one place to another because "she no longer needs that level of support." When supports and housing are separated, the staff can "withdraw" or "fade" instead of the person needing to move to a new location. This results in continuity for the person and again builds on existing supports. Also, when a person needs more or different supports, he or she can continue living in the same place, but the supports can be changed.

In many ways, this flexibility is much more difficult for service systems to achieve than individualization. We may "individualize" once, but our systems are not often designed to adapt and change at the pace that people change. Flexibility has been built into this approach by keeping decisions as close as possible to the people being supported.

The development of supports

An individualized approach to supports typically involves a change in our way of thinking about "assessment" and "service development."

• **Community Assessments** - Unlike the typical "deficit-based" assessment, a community assessment involves a less formal process of getting to know the person in a variety of community environments. The emphasis is not on screening in or out of services, but on using the assessment process to determine the supports that will be initially needed. For a good discussion of this type of assessment, see *Getting to Know You: One Approach to Service Assessment and Planning for Individuals with Disabilities* (Brost and Johnson, 1984). More structured ecological strategies (Ford et. al., 1984) can also be used.

Under the Wisconsin Community Integration Program Medicaid Waiver, all assessments must include social relationships, meaningful education or vocational programs, recreation and leisure activities, health and wellness monitoring, social and physical integration in the community, involvement of family and friends, home and protection of individual legal rights.

• **Building on Natural Community Supports** - An individualized approach to Supporting adults in the community builds on the existing community ties and relationships that each person already has. Instead of supplanting these ties, this approach looks at how these natural supports can be both maintained and strengthened, if that makes sense in the life of the person. Just as Ed Skarnulis (the Minnesota State Director of Human Services) said, "Support, don't supplant the family." it is also important to support neighbors, friends, acquaintances and other relationships in the person's life.

Many of the supports that people with disabilities need are already available through "generic" or community services available to the general public. An individualized approach includes an emphasis on using these existing supports as opposed to the creation of segregated supports and services.

• **Changing our Thinking About Supports** - This approach requires a shift in how we think about the development of supports and services. In order to facilitate a change in our thinking, a technique called personal futures or lifestyle planning (O'Brien, 1987) has been used to help groups of people create a positive future vision for the life of a specific person with a disability.

This approach is one useful way of beginning to break away from "fitting people into services" and moving toward developing the supports that enable the person to lead a meaningful life. It also asks key questions about what we can do to make this vision occur as opposed to our current focus on what the persons themselves must change.

The way in which we think about supporting people seems to be one of the main impediments to changing to a more individualized approach. While funding mechanisms, regulations and other structures are not always designed to support individualization, often simply shifting our thinking can assist us to recognize options even within current constraints. As one staff member said, "It can be done. It is a problem in thinking."

• **Choice of Support Providers** - The best examples of supporting individuals included consumer control over the hiring and firing of their staff. In these situations, the staff worked for the person with a disability, not for the agency. The role of the agency was to support the person in managing his or her staff, including the aspects of hiring and firing. As agencies move out of the housing business, their role in the area of support services can also be expected to change. In this area, developmental disabilities services have a tremendous amount to learn from the independent living movement in this country.

Even when people with disabilities do not directly hire or fire their own staff, it is critical that mechanisms be established to provide for staff turnover during the contract period. There are times when a person and his or her support providers will not be a good match, therefore mechanisms to facilitate a change in providers must be in place.

• **Availability of Supports for People with Severe Disabilities** - Another element that differentiates this approach is the availability of supports. Unlike "supportive apartments" or semi-independent living which typically support people with mild disabilities, this approach enables people with severe disabilities to live in an apartment or home with the supports that they need. For some, 24-hour a day support services are critical. Some agencies we visited were able to discontinue the continual uprooting of people with severe disabilities from their living quarters by helping them to move into their own homes and still maintain the ongoing supports that they required.

• **Increased use of Physical Adaptations** - This type of approach also appears to increase the physical adaptations that are made for individuals. When living in one's own place comes first, doing it all on one's own (i.e., process) may become secondary to getting it done (i.e., outcome). Thus, people can be supported in living meaningful lives before they are able to do it all on their own. We have been continually impressed with the inexpensive innovations that staff, family and the people themselves have developed (e.g., cassette tapes of morning routines strings on cupboard doors) to support people in living in their own homes.

• **Supporting People vs. Independence** - A critical issue raised by this approach is the differentiation between helping people to become independent and supporting people in the community. As a reaction to the custodial care of the past, in this decade there has been an increased emphasis on the potential for growth, development and independence of people with mental retardation. While this has been a positive step forward, the interdependence of people has often been overlooked for people with disabilities. A more individualized approach tends to build on existing natural networks of family, friends and associations; provides training and support within the context of home and community and does not require that a person attain certain skills in order to have the right to live in the community and in a home.

Conclusion

This article primarily examined some of the key elements in individualized supports based on learnings from existing programs. Future articles will provide more information on other key elements, such as enabling structures (i.e., funding, training, individual services coordination and other administrative issues) and future directions and issues.

References:

Brost, M. M. & Johnson, T. Z. (1984). *Getting to Know You: One Approach to Service Assessment and Planning for Individuals With Disabilities*. Madison, WI: DHSS- DCS.

Ford, A. et. al. (1984). "Strategies for Developing Individualized Recreation and Leisure Programs for Severely Handicapped Students." In **N. Certo, N. Haring & R. York** (Eds.), *Public School Integration of the Severely Handicapped: Rational Issues and Progressive Alternatives*. Baltimore: Paul H. Brookes. (pp. 245-275).

Johnson, T. Z. (1985). *Belonging to the Community*. Madison, WI. Options in Community Living.

O'Brien, J. (1987). "A Guide to Life-style Planning." in **G. T. Bellamy and B. Wilcox** (Eds.), *A Comprehensive Guide to the Activities Catalog: An Alternative Curriculum*. Baltimore, MD: Paul H. Brookes Publishing Co.

Taylor, S. J., Racino, J. A., Knoll, J. A. & Lutfiyya, Z. (1987). **The Nonrestrictive Environment: On Community Integration for People with the Most Severe Disabilities.** Syracuse, NY: Human Policy Press

Taylor, S. J. (1986). *Community Living in Three Wisconsin Counties*. Syracuse, NY: Center on Human Policy.

Walker, P. (1987). *Report on Centennial Developmental Services, Inc., Weld County, Colorado*. Syracuse, NY: Center on Human Policy.

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APPENDIX II

Smith, G., & Getting R. (1988, draft). An assessment of services to South Dakota's citizens with developmental disabilities. Alexandria, VA: National Association of State Mental Retardation Program Directors.

RECOMMENDATION IV: ***South Dakotans should examine the experiences of other states that have used supported living arrangements as a means of meeting the diverse residential services needs of persons with developmental disabilities and determine the steps necessary to implement such programs across the State.***

The supported living arrangement model of delivering residential services is increasingly being recognized as a means of better tailoring services to individual need. As with supported employment, we believe that South Dakotans should carefully examine the potential applicability of this approach in their State.

The supported living arrangements model is based on the concept that persons with developmental disabilities should be placed in the most appropriate integrated living setting and the level of services furnished to any given individual should be regulated by his or her specific needs. As such needs change, services will vary but the placement site will remain constant. Usually, supported living arrangement programs employ apartments in integrated complexes or foster families as the placement of choice. Support services, ranging in intensity from constant oversight and supervision coupled with intensive habilitation and personal care services to periodic client contacts with limited training services, are furnished based on client assessments. The supported living arrangements model explicitly rejects the notion of a "residential continuum" and accords no special role to services provided in separate, group living arrangements.

In states such as Colorado and North Dakota, the use of supported living arrangements has largely displaced the development of new group homes, particularly with regard to meeting the needs of persons with relatively complex service requirements. Supported living arrangement programs have proven sufficiently flexible to support persons representing a wide range of needs. For example, in both Colorado and North Dakota, such arrangements are now the placement of choice for persons exiting state-operated institutions. In each instance, such placements have permitted these states to reduce their reliance on institutional settings to levels well below that of South Dakota. Antecedents of the programs in Colorado and North Dakota may be found in the community living arrangements program that has been in operation for many years in Pennsylvania as well as programs pioneered at the Macomb-Oakland Regional Center in Michigan. The ability to tailor services to individual needs appears to permit settings serving one-two persons to be operated as economically, or even more economically, than group homes.

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In our judgment, promoting the use of supported living arrangements would substantially improve the range of residential services available to persons with developmental disabilities in South Dakota. Not only would this approach result in improved client outcomes but it also would avoid many of the difficulties associated with group home development (including capital accumulation and the inevitable issues associated with group home siting). In addition, based on the experiences of other states, supported living arrangement services would: (a) provide greater assurance that scarce dollars are used most effectively; and, (b) help to energize the service delivery system to find creative solutions to the specific challenges associated with managing such services. In Colorado, for example, a number of existing providers have divested themselves of group homes in favor of operating supported living arrangements.

In our judgment, South Dakota has created unnecessary rigidities in its residential services array by viewing group homes as the principal setting in which persons with relatively intensive needs must be placed to receive services. Such a rigid perspective inevitably constitutes a substantial barrier to expanding residential services, given the costs and inherent limitations associated with group living models. On a *de facto* basis, placements in more integrated settings, such as apartments or family homes, have been limited to persons with less intensive needs. While such a policy is not uncommon in other states, recent experiences in some states strongly suggests that the conventional wisdom regarding the type of residential setting needed by clients is seriously flawed and ultimately detrimental to their best interests.

We strongly recommend that State officials, service providers, and other interested parties explore, in detail, the experiences of other states in promoting the use of supported living arrangements, either through on-site visits to the states cited here or by inviting key system actors to South Dakota to present information on their experiences with this model. We also recommend that a special work group be established to identify the steps that would need to be taken in South Dakota to implement such services. In this regard, it is worth noting that the Center on Human Policy at Syracuse University has a federal grant to furnish technical assistance to states interested in organizing such residential programs.

Upon completing its exploratory study, the proposed work group on supported living arrangements should prepare a system-wide report detailing the results of its analysis as well as its recommendations concerning future actions.

APPENDIX III

APPENDIX III: METHODOLOGY

This policy analysis was based on data collected between October 1988 and August 1989. The principal investigator for this analysis completed two on-site visits to the state, conducted all meetings related to the project, and also participated in interviewing. All observations and most interviewing were based on a qualitative research approach (Steven J. Taylor & Robert Bogdan, An Introduction to Qualitative Research Methods. New York: John Wiley, 1984).

Interviews with ATC directors were conducted by four project staff, using a semi-structured interview format. These interviews averaged two hours in length and concentrated on the following areas: background on the organization; strengths and weaknesses in community living; capacity to support people with severe disabilities; individual assessment, planning and funding; staffing and supervision; housing/home ownership; relationships with other organizations; relationships with parents/people with disabilities; quality assurance; funding; and community integration.

The following are specific activities conducted as part of this policy analysis:

1) On-site observations at nine Adjustment and Training Centers during January 1989 and April 1989, including Mitchell, Chamberlain, Northern Hills, Sioux Vocational, Black Hills, ECCO, United Cerebral Palsy, Huron, and OAHE;
2) On-site observations at five supervised apartment sites, four monitored sites, one independent apartment, and eight community residential facilities operated by the Adjustment and Training Centers;
3) On-site observations at a community residential facility and apartments operated by one cooperative;
4) On-site observations at Custer, one of the state institutions;

5) Interviews with the superintendent of Custer and a member of the Board of Charities and Corrections (which was in existence at the time of the interview);

6) Interviews with the director of each Adjustment and Training Center;

7) Interviews with representatives of the South Dakota Advocacy Project, the Citizen Advocacy Project, the Vocational Rehabilitation Advocacy Project and the University Affiliated Program, the Center for Developmental Disabilities;

8) Interviews with state representatives of the DSS' Office of Adult Services and Aging, the Section on Special Education of the Department of Education and Cultural Affairs, DSS' Office of Medical Services, and the Division for Developmental Disabilities;

9) Interviews with five people with developmental disabilities who are currently using community services and five parents;

10) Interviews with program and/or casemanagement staff at nine ATCs;

11) Interviews with representatives of the cooperative most involved in the provision of residential services in this state;

12) Joint meeting with approximately 35 casemanagers from around the state;

13) Joint meeting with ATC directors at their association meeting in May 1989;

14) Two meetings with a steering committee for the project, including parents and people with disabilities;

15) Joint meeting with staff of the Division of Developmental Disabilities;

16) Review of materials obtained through the Adjustment and Training Centers, including sample program descriptions, assessment tools, and individual plans, among others;

17) Review of a variety of state planning and policy documents, including the state plan and the NASMRPD report, current regulations, and financial documents such as the Home and Community-based Medicaid Waiver application.

This analysis also draws on information obtained through a consultation on behalf of the South Dakota Department of Education and Cultural Affairs in July 1988. This included a visit by the principal investigator to Redfield, another state institution, meetings in six South Dakota towns, as well as a review of information on the special education cooperative system and the status of supports for families and their children in South Dakota.

The analysis also relies on data collected nationally on promising practices in the area of housing through a subcontract with the University of Minnesota. This data included a national search for places demonstrating promising practices through the use of such mechanisms as cooperatives, trusts, housing subsidies, and creative financing, and a review of selected resource materials. In addition, telephone contacts were made with national leaders in housing on specific issues of relevancy to South Dakota (e.g., HUD mortgages).

This analysis is based on our ongoing study of "state-of-the-art" practices in integrating people with severe disabilities in the community conducted through our Research and Training Center on Community Integration and through a subcontract with the University of Minnesota Research and Training Center on Community Living.

The authors would like to thank Patti Miles for coordinating the work related to this project, all the people who participated in the data collection, particularly those who opened up their homes for this study, and Rachael Zubal for her extensive work on this report.

APPENDIX IV

APPENDIX IV

QUALITY ASSURANCE FRAMEWORK

Prepared by:
Steven J. Taylor, Ph.D.
Center on Human Policy

Assumptions:

(1) There are no "guarantees" of quality in any system; no infallible method or single approach exists that will assure high quality services.

(2) Quality cannot be mandated; the most that can be strived for is basic safety and rights protections.

(3) Multiple approaches to quality assurance offer the best promises.

(4) There are different ways of approaching traditional facility-based services and flexible, non-facility-based services.

Conceptual Framework

I. Top-down Approaches
- oriented toward safety and rights protections
- mandated and encouraged
- works best for facility-based services (e.g., group homes; ICF/MR)

1. Regulations/Licensing/Certification/Formal Monitoring
   - Minimum standards and requirements for monitoring

2. Guidelines (encouraged)
   - Policies need to set forth mission

3. Rights Protection
   - Protection and Advocacy
   - Ombudspersons
   - Grievance Procedures for consumers/guardians

II. Bottom-up Approaches
- formal and informal
- maximize range of approaches
- recognize difference between facility-based and non-facility-based
- basic strategy is "eyes-on"

A. Formal
   1. Empowered case management
   2. Requirement for quality of life guidelines to be developed with procedures (e.g., Options)
   3. Composition of Board of Directors to include parents/consumers
   4. Citizen Advocacy to be funded by state
   5. Citizen Review Committees/Neighbors
   6. Requirement for agency evaluation
      - Self-evaluation - specify minimum requirements; should include interviews and observations with written report (e.g., Region V, Nebraska Systems Review*)
      - Agency - arranged external evaluation - based on similar criteria

B. Informal
   1. Promote relationships/friendships
   2. Right of access to facilities by parent/consumer organizations
   3. Citizen-initiated reviews (e.g., Macomb Oakland Regional Center parent monitoring*)

*These materials are also available through the Center on Human Policy or can be requested directly from these organizations.

APPENDIX V

Appendix D
Options Policy on Quality of Life*

Introduction

The mission of Options in Community Living is to provide support and coordinate services to enable adults with developmental disabilities to live on their own in small, integrated community settings. The agency works with people to help them make their own choices and reach their own goals, with support available as often and for as long as it is needed.

Because our clients rent their own apartments which are not subject to licensing, any government regulations, or agency control, Options felt a responsibility to develop quality-of-life standards that apply to people who live in apartments or other similar community residences. We maintain that the expectations for quality of life for persons with disabilities should be the same as those for other members of the community. Support must then be provided on an individualized basis to help our clients achieve these standards.

The purpose of this document is three-fold. First, it serves to provide staff with standards for evaluating an Options client's well-being and for identifying areas where intervention is needed. Secondly, it provides the agency with guidelines for determining which individuals or groups are best served by this service model. These standards are not intended to be used as entrance criteria, but rather as a general framework for assessing community living needs.

The third purpose is to communicate to our consumers, their families, advocates, and professionals the principles that guide our services. We encourage open dialogue with our consumers and other interested parties about these principles and how they are implemented.

The policy addresses nine major aspects of community living. Each area is divided into two sections: 1) a list of those conditions that we feel must exist to ensure that people are not at risk in the community, and 2) a list of further conditions that Options will actively promote to help its clients achieve a valued lifestyle. It is anticipated that some people will need intensive and long-term support to maintain these standards.

A final comment must be made about the implementation of this policy. We believe that the responsibility for quality of life is shared by service providers, the consumer, and significant others. Options' services are voluntary and we will actively promote, but cannot enforce, these standards. We respect the right of our consumers, with support from their families and advocates, to assume responsibility for their life decisions.

I. Autonomy/Choice

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has opportunities to make decisions and express preferences in all areas of life. The right to make these decisions shall be respected by others in the person's life (e.g. service providers, parents, roommates). The person also has the right to refuse interventions initiated by providers.

2. The person has methods of expressing preferences and a method of acting upon these preferences in all areas of life. For example, a person who has a physical disability and is nonvocal might use a communication board to express preferences and have a personal care attendant to act on those preferences. Preferences can be expressed in nonverbal ways, such as by a change in behavior.

3. The person has access to information and experiences that assist the person in making decisions about his/her life.

4. The person has people in addition to service providers for support and information needed to make decisions about his/her life (e.g. family, friends).

*Options in Community Living, Inc., 1864 E. Washington Av., Madison, WI 53704. Copyright 1987

II. Personal Income

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has a stable source of income that covers basic living needs, including shelter, food, transportation, clothing.

2. There is effective management of this income to ensure that basic needs are met. (Support can be provided when needed through a double-signature bank account, representative payee, or assistance with budgeting.)

B. Conditions that will further promote a valued lifestyle:

1. There is sufficient income for items and activities that enrich one's life experience, such as vacations and other leisure activities, home decorations, and items that enhance one's personal appearance.

2. The person is able to participate as fully as possible in decision-making about the use of personal income through the development of money and budgeting concepts and values that encourage financial responsiblity.

3. The person can maximize income through wise investments and purchases, and through subsidies for which the person is eligible.

4. The person has a means of earning income through employment as a supplement to or in place of government benefits.

III. Housing

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has housing that meets community building codes, is secure and has adequate heat, water and electricity.

2. The person has the basic furnishings necessary for daily living, including a bed, chairs, table and lighting.

3. The person lives in a neighborhood where s/he feels safe and where there is access to needed resources.

B. Conditions that will further promote a valued lifestyle:

1. The interior and exterior of the home is maintained in a safe, clean and attractive fashion.

2. The person is able to exercise control over the home environment, including the choice of location, personalized furnishings and decor, and control of temperature and lighting.

3. The home furnishings are attractive and complete.

4. The person is able to have maximum influence over his/her housing situation through such means as participation in a tenant association, cooperative housing or home ownership.

IV. Physical and Mental Health

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person's health is maintained through adequate nutrition, exercise, safe behavior, medical monitoring, and appropriate medications when needed.

2. The person receives prompt and up-to-date treatment for physical and mental health problems.

3. The person employs a personal care attendant if his/her physical disability limits the person's ability to provide self-care.

B. Conditions that will further promote a valued lifestyle:

1. The person has established relationships with and easy access to health care providers (e.g. physicians, nurses, dentists, counselors and therapists) who know the person and monitor his/her health needs on an ongoing basis.

2. The person's lifestyle encourages wellness. For example, the person eats nutritious meals on a regular schedule and maintains an appropriate weight; does not smoke; does not drink in excess or use drugs; has coping mechanisms to relieve stress; has people to provide emotional support.

V. Safety

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. Potential dangers in the person's environment are minimized. For example, his/her home is free of fire hazards and is locked and secure; the person does not walk alone on dark streets at night.

2. The person receives prompt and appropriate emergency services when needed, such as police, fire department, ambulance, crisis line.

VI. Appearance and Hygiene

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person minimizes health-related problems through adequate personal hygiene and clothing choice that are appropriate for weather conditions.

2. The person maintains acceptable hygiene and appearance so as not to restrict where s/he can live, work and socialize.

B. Conditions that will further promote a valued lifestyle:

1. The person has a choice of attractive clothing for different occasions.

2. The person maintains his/her hair in a manner that is becoming.

3. The person's hygiene and appearance serve to enhance self-esteem.

VII. Relating with Others

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has the means to communicate on a daily basis with primary people in his/her life. (This may include speech, signing and adaptive devices.)

2. The person has support people, including Options staff, with whom s/he is able and willing to maintain contact.

B. Conditions that will further promote a valued lifestyle:

1. The person has the means of communicating in such a way that encourages interactions with other members of his/her support system and community (e.g., clarity, assertiveness, appropriate affect).

2. The person has supportive relationships with family members that encourage independence.

3. The person has relationships with friends and peers that provide companionship, intimacy and support.

4. The person has the opportunity to responsibly engage in sexual relationships and marriage based on his/her personal beliefs and values.

5. The person's relationships include people who are nondisabled.

VIII. Meaningful Activities

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has a daily routine that is designed around his/her needs and capabilities and that resembles as closely as possible a typical adult routine. Such a routine is likely to include vocational, domestic and leisure activities.

B. Conditions that will further promote a valued lifestyle:

1. The person's activities provide opportunities for personal growth and increased life satisfaction.

2. The person receives wages for work.

3. The person takes part in culturally valued leisure activities, such as parties, trips, concerts and shows.

4. The person's activities take place in community settings that are integrated with nondisabled people.

5. The person has the means of developing and achieving short-term and long-term goals (e.g., vocational planning, vacations, retirement).

IX. Mobility

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has the means to move about his/her home and community environments to the extent necessary to satisfy basic needs.

B. Conditions that will further promote a valued lifestyle:

1. The person has physical access to a wide range of community resources for work, leisure, shopping, etc. Modes of transportation can include bus, car, bike, walking, vehicles equipped for wheelchairs.

2. The person, when needed, has adaptive devices that will enhance mobility, such as a cane, motorized wheelchair, three-wheel bike.

APPENDIX VI

SELECTED ASPECTS OF INDIVIDUALIZED FUNDING AND SUPPORTS FOR ADULTS IN OTHER STATES

Minnesota Home and Community Based Medicaid Waiver*

Separation of Housing and Supports

1. Supports can be provided in a person's own rented or owned home as well as in an agency facility or an adult foster home.
2. A person can live in a variety of kinds of housing and still receive support.
3. A person can be involved in locating and selecting the home.
4. A person can live alone or with others and can have a choice of roommates.

Home Ownership

1. Does not encourage this to occur, but allows for providing services in a person's own home either leased or owned under certain circumstances.

Individualized Supports

1. A range of different services can be provided to adults in and out of their home, including recreation/leisure, behavior programming, community integration, menu planning and dietary, budgeting, counseling on sexuality, bus training, safety/survival skills, home maintenance and community orientation. Additionally, nursing, psychological, personal care, occupational therapy, communication consultation, behavior consultation, and related services are available.
2. Plans and budgets are developed for individual people; an average cost across people served must be maintained at the county level; counties can access a special fund for individuals whose support needs greatly exceed the average.
3. Amount, frequency, intensity, and duration of services is dependent on the needs of individuals.
4. Services are determined through an individual planning process.

Flexible Supports

1. Contracts can be renegotiated between the private agency and the county during the course of the year.
2. Workers can be hired an temporary contracts to perform services for as long as people need those specific services.
3. Times when supports are provided can be changed dependent on the person's schedule and needs.
4. Amounts of different supports may vary over the course of the year.

Availability for People with Severe Disabilities

1. This is both a deinstitutionalization and a diversion waiver; designed for people at ICF-MR level of care; respondent indicates that some of the people with the most severe disabilities may not yet be served.

*Information based on site visit 8/87, telephone interview with Medicaid waiver manager in May 1988, and waiver application. This analysis was completed in June, 1988.

Minnesota Home and Community Based Medicaid Waiver (continued)

Choice in Support Providers

1. The county can contract with different providers for different services that a person may need or one provider can offer a number of different services; input of the person may be solicited before decisions on providers are made.

Issues

1. Stringent informal criteria used for determining when supports will be provided in a persons's own home; less than 5% of supports are offered in a person's own home.
2. Available only through the waiver.
3. No mechanisms available to allow for people to hire their own attendants or to grant money to person/family for purchases.
4. A variety of implementation issues, including maintenance of average cost of county level and change in thinking of provider community from ICF-MR model.
5. Still results in "boxes" of services; supportive living services are generally 24-hour support and are funded through the Medicaid waiver; if a person needs substantially less support, must be funded as semi-independent living through state/county funds.
6. Heavy reliance on foster care licensing has created problems in using this mechanism for supporting adults.

Michigan Supported Independence Program*

Principles of the Program
(from Michigan Department of Mental Health Services Standards, 7/31/87)

1. The program must provide the participants with as much autonomy as possible.
2. The program must be designed to meet the needs of the participant, i.e.: location, type of residence, staff support, etc.
3. The program must be flexible and responsive to changes in the participant's needs, particularly with regard to staff support. Providers must be able to add or withdraw support as the participant and his/her "I-team" deem appropriate.
4. The participant is an active member of the "I-team." His/her preferences for living situation, roommate arrangements, employment are very seriously regarded.
5. The residence (home, apartment) is that of the participant(s), not the staff or provider. Professional staff should observe the same courtesies they would entering anyone else's home.
6. Each site will serve no more than 3 people.
7. Wherever possible, the person's current "I-team" should continue to provide support services in their new residence.

Additional Highlights
1. The contract rate is based on the recipient's utilization of approved service categories and may be adjusted as services change.
2. Exceptions request mechanism also used for the supported independence program to increase added support when needed.
3. Program has made extensive use of home modifications to adapt places to meet the needs of individual people.
4. Assessments include a focus on: client training needs and needs for supervision/assistance, staff training needs, needs for specialized or adaptive equipment, recommended type and frequency of service contacts, recommended staffing, and needs/recommendations for special services.

Issues
1. Plans are developed for individual people, but cost centers become the home; aspects of contracting process (e.g., 95% occupancy rate) based on group as opposed to individuals.
2. Greater availability for people with severe physical disabilities as opposed to severe intellectual limitations; person must be able to live in the community without "continuous supervision" as opposed to supports.
3. Team recommendations tend to lean toward oversupervision initially.
4. A variety of implementation issues, including assisting state personnel and private providers to change to a new approach.
5. Initial lack of a mechanism for a participant to change to a new provider during the contract period if so desired.
6. No provision for the person hiring their own attendant; all staff are hired by the provider.
7. Little emphasis on building on natural supports in the community.

*Based on site visit in Fall 1987 and review of statewide guidelines for the supported independence program. This analysis was completed in June, 1988.

Wisconsin Community Integration Program
Home and Community Based Medicaid Waiver*

Highlights

1. The individual assessment process is a particular strength. "The purpose of the assessment is to gather current, valid information about each specific person and his/her community environment in order to determine what service, supports, or other environmental modifications would be necessary to enable a person to live and participate in the community with as much dignity and value as possible." Areas such as informal supports, personal preferences and social participation are included.
2. There is an average amount of money available for each person funded by the Medicaid waiver; counties can fund some people at higher or lower amounts as long as the average is maintained at the county level.
3. Individual service plan includes different service categories, unit cost and frequency; some selected examples of service categories include personal emergency response system (CIP II), communication aids (CIP II), housing modifications (CIP IA, IB, and II).
4. Possible for counties to combine various funding streams to support people in the same home.
5. It is possible for a person to live in a home they own or rent and still receive supports.
6. Plans and service costs are tied to individual people; if a person moves, their funds follow them.

Issues

1. Service categories still include facility based services such as group homes, but limit of four people in a home unless a waiver is granted.
2. Slow process of working with counties to change to a more individualized approach to supporting people in the community.
3. While people with severe disabilities have been served in the community through the waiver, initially there were some limitations based on the average amount of money available.
4. There does not seem to be any mechanism to change the supports a person is receiving in a timely way or for the person to change their provider.
5. The waiver is focused on deinstitutionalization; lack of diversion funding creates inequities in supports between people who have lived at home and people who have been institutionalized.

*Information based on site visit in 1986 and review of the Medicaid waiver application. This analysis was completed in June, 1988.

North Dakota Home and Community Based Medicaid Waiver*

Highlights

1. Service costs paid for through the Medicaid waiver include habilitation (training the person in particular areas of daily living) and personal care services (assisting or maintaining the person receiving services); costs covered include direct care staff salaries, transportation and consulting services as well as indirect costs.
2. Individualized rates are established for each person; contract is for each person.
3. Staffing can include a variety of options such as live-in staff in the person's apartment/home, direct care support hours to maintain the placement, paid neighbors, and paid companions.
4. Service intensities (for staffing) can vary from relatively minimal to 24-hour shift staff.
5. The budget is developed concurrently with the interdisciplinary team process.
6. Supplements for housing can also be included as part of the individual rate setting process.

Issues

1. Primarily developed as part of a continuum of services, although eligibility criteria state that people can move directly from Grafton (the state institution).
2. Agreements are with one provider to give all supports; no mechanism appears to be set up for change during the contract period.
3. North Dakota plans to make major changes in its waiver based on its experience.
4. The entire staff must be employees of the contracting providership; no option for the person with a disability to employ; all relationships defined as employer-employee relationships.
5. Implemented to insure that costs are decreased over time.

*Information based on review of written material; site visit, fall 1988.

Also see Colorado, individually negotiated rates (Smith & Alderman, 1987).

APPENDIX VII

NEW DIRECTIONS IN HOUSING FOR PEOPLE WITH SEVERE DISABILITIES: A COLLECTION OF RESOURCE MATERIALS

Prepared by:

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December, 1989

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INTRODUCTION

This information package is specifically designed for people who wish to explore a "housing/support services" approach in their state, region and local communities. It provides an introduction to housing strategies and resources that can be used to promote home ownership by parents and people with disabilities, to make all housing more accessible, and to increase the development and use of small, integrated housing options.

Based on the right of an adult to live in a home in the community with the necessary supports, this "housing/support services" approach is also called an "individualized," "non-facility based," or "person-centered" strategy. Its primary service characteristics include: (1) the separation of housing and support services; (2) the promotion of home ownership and integrated housing; (3) individualized and flexible services and supports; (4) individual assessment, planning and funding; and (5) consumer-directedness in housing and services. More detailed information on this approach can be obtained by writing the Center on Human Policy, Syracuse University, 200 Huntington Hall, Syracuse, NY 13244-2340.

The areas highlighted in this information package (i.e., the use of trusts for housing, the development of cooperatives and housing associations, housing subsidies, housing resources and organizations) are samples of the wealth of materials available on housing. These materials are designed as a bridge between the housing and disability fields in order to (a) expose people in the disability field to information on integrated housing options and financing; (b) promote greater exchange and encourage the development of new networks on housing issues; and (c) increase the awareness of housing organizations on the inclusion of people with disabilities in community living.

TRUSTS AND HOUSING

One method of promoting home ownership by parents and people with disabilities is the establishment of housing trusts, a relatively new phenomenon in community development financing. Since 1985, the number of housing trusts in the country has increased more than fivefold in response to the growing demand for housing resources (Center for Community Change, 1989).

Housing trust funds are dedicated sources of revenue* (e.g., real estate tax sales, interest on real estate escrow accounts) committed to the purpose of providing low and moderate income housing. They are generally established by local, county or state government and are usually ongoing and permanent. Some housing trusts have been created on the state level through a budget allocation rather than an ongoing commitment of revenue (Center for Community Change, 1989). In addition, private trusts, established for the benefit of individuals or groups, may also include a housing component.

This section describes several types of housing trusts, including community land trusts, community trusts established through private-public cooperation, and private trusts. It also discusses the need for a national housing trust fund. The potential of housing trusts remains largely untapped for supporting people with disabilities to live in homes of their own.

*Many of the terms used in this information package are included in the glossary.

I. ORGANIZATIONS*: TRUSTS AND HOUSING

Illinois Self-Sufficiency Trust
340 West Butterfield Road
Elmhurst, IL 60126
312-832-9700
Contact: Paul Medlin, Senior Vice President
Self-Sufficiency Trust Program

The program began in Illinois in March 1988 as a product of research and support through the National Foundation for the Handicapped. The self-sufficiency trust (SST) is a comprehensive life-care planning option that can assist parents and families in meeting some of the long term support needs of their family members with disabilities without losing their governmental benefits. Families can invest modest sums of money in SST and income from the trust can then be spent for long term care, therapy and other services that the person may need. A segment of the trust fund is controlled by a Charitable Trust Fund which accepts residual and donated assets for low-income persons from private contributions, corporations and/or foundations.

SST has developed a computerized data base which they feel offers them the ability to help families prioritize what the person with the disability will need and what SST will be able to provide. They can also pool information and assist groups of people or families with similar needs, interests and resources to work together. Another claimed benefit of such a computer-based system is in aiding the state to look at future service needs. One concern, however, would be that a computerized look at planning a person's future will not take into account individual needs and

*Information presented in this resource package is based on telephone interviews and a review of written resources.

differences but only increase the systemization of the individuals with disabilities and packaging of their futures. Some families may prefer to establish individual trusts than use a statewide program. SST hopes to develop a nationwide demonstration model that will be adopted by every state.

Virginia Beach Trust Program
Pembroke Six, Suite 218
Virginia Beach, VA 23462
804-499-7619
Contact: Patti Phelps, Associate Director, MR/DD Programs

The Virginia Beach Trust Program (VBTP) is a collaborative effort between public and private sectors which have formed a private non-profit association. It initially set up trusts for parents which would offer supports to their children with disabilities. In the past year, at the request of some of the parents, VBTP has added provisions to set up housing trusts. The program, which is available to the local community, provides free on-going consultation to interested families. VBTP also offers information on developing a community trust program. Current efforts are oriented toward setting up trusts to develop group homes, but the same concept could be used more creatively to support adults to live in homes of their own.

Housing Trust Fund Project
570 Shepard Street
San Pedro, CA 90731
213-833-4249
Contact: Mary E. Brooks

The Housing Trust Fund Project (HTFP) is an effort sponsored by the Center for Community Change in Washington, DC through a grant to put together information about the development of housing trust funds through the country. It is also focused on the promotion of neighborhood organizations in creating trust funds

that benefit those most in need of housing. The project has produced several books including, **A guide to developing a housing trust fund** and **A survey of housing trust funds**, which are referenced in the resource materials.

Community Land Trusts
Institute for Community Economics
151 Montague City Road
Greenfield, MA 01301
413-774-7956

The Institute for Community Economics is a private, non-profit corporation founded by community residents to remove land and housing from the market to ensure long-term affordability of housing while securing the control of the community over land. Community land trusts (CLTs) provide for a variety of community development activities including construction of new housing, rental housing, housing cooperatives and the rehabilitation of existing structures.

CLTs attempt to meet the needs of people least served by the existing market and prohibit absentee ownership of land and housing. Their goal is to promote ecologically sound land use practices and preserve long-term affordability of housing. CLTs buy or receive gifts of property. The Institute for Community Economics offers a revolving loan fund to communities interested in developing CLTs in order to finance acquisition and construction. The Institute may also cooperate with existing efforts already happening in a community.

II. RESOURCE MATERIALS: TRUSTS AND HOUSING

TITLE: A survey of housing trust funds

AUTHOR: Center for Community Change

PUBLICATION INFORMATION: 1989, January

Center for Community Change
1000 Wisconsin Avenue, N.W.
Washington, DC 20007
(202-342-0519)

COST: Community-based organization - free; Non-profit organization and public agencies - $7.50

TITLE: A guide to developing a housing trust fund

AUTHOR: Center for Community Change

PUBLICATION INFORMATION: 1989, January

Center for Community Change
1000 Wisconsin Avenue, N.W.
Washington, DC 20007
(202-342-0519)

COST: Community-based organization - free; Non-profit organization and public agencies - $10.00

The first of these two 100 page manuals offers an overview of housing trust funds describing how they work, what they have done, where they exist, and who to contact for further information. It also includes profiles of housing trusts in 34 states. The second book presents a guide to developing housing trust funds. Here

the reader is given an overview, principles for developing housing trust funds, different models of administration, revenue sources and information on program issues (e.g., eligibility). Both books provide a bibliography for further reference.

TITLE: A guideline for developing a community trust program

AUTHOR: Field, P.

PUBLICATION INFORMATION: 1982

The Virginia Beach Trust Fund Program
for Developmentally Disabled People and Their Families
Pembroke Six, Suite 218
Virginia Beach, VA 23462

COST: $14.50 (entire package including guidelines)

This 23 page outline lists the specific steps one organization took in establishing a community trust fund. It would be most useful to staff who are responsible for developing and implementing such a program. This information packet also includes a sample of a master trust agreement, instrument of adoption, exempt trust fund, beneficiary information review form, and organizational flow charts. Newspaper articles, a program brochure, and a list of trust and service programs are also provided.

TITLE: Affordable housing: The American Day Dream

AUTHOR: Rosen, D.

PUBLICATION INFORMATION: 1988

Business and Society Review, No. 67, Fall 1988.

The article discusses the need for a national housing trust that can provide a "predictable, adequate revenue source needed to sustain an affordable housing production and preservation." Rosen argues that in combination with a coherent national housing policy and existing federal, state, local and private sector investment, a national housing trust could help meet the nation's needs for low and moderate income housing. This idea of a large scale, affordable housing program of new construction, rehabilitation and preservation that is self-financing and permanently endowed may be a piece of what will regenerate housing in America.

Rosen discusses how trust funds have been used in the past in the Social Security Trust Fund, National Highway Trust Fund, and Airport Safety Trust Fund. All were created nationally in response to strong needs and capitalized by self-financing. The nature of the housing crisis in this county, Rosen claims, requires such large scale commitment. Seventeen states and numerous localities have already enacted such programs.

TITLE: Attorney handbook: Estate planning for persons with disabilities

AUTHOR: Sheen, T. M.

PUBLICATION INFORMATION: 1988

Illinois Self-Sufficiency Trust
340 West Butterfield Road
Elmhurst, IL 60126
312-832-9700

COST: No charge

This is one of the resources in an excellent information package available from the Illinois Self-Sufficiency Trust (SST) and produced in conjunction with the National Foundation for the Handicapped. The manual includes highlights of Illinois state law, detailed information on the SST including its relationship to other federal funds such as Medicaid and SSI, taxes, trust participation and services. In addition, the appendix includes sample documents.

TITLE: The community land trust: A new system of land tenure

AUTHOR: Institute for Community Economics

PUBLICATION INFORMATION: 1986, June

Institute for Community Economics
151 Montague City Road
Greenfield, MA 01301
413-774-7956

This paper presents an overview not only of what a land trust is but the principles that direct community land trusts. The problem of how we use our land today is defined followed by a CLT approach to dealing with these problems. The article takes the reader through a brief description of how the CLT works and describes advantages of such an approach.

HOUSING SUBSIDIES

Housing subsidies are one method of insuring that people with disabilities can live in decent, typical homes. A subsidy approach can be a particularly useful strategy when a community has an available supply of good housing that is not affordable to many people with disabilities.

A housing subsidy is simply financial assistance given by a governmental unit to an individual, organization or other governmental entity for the purpose of housing and related costs. There are many types of housing subsidies, three of which are included in this section:

* federal "mobile" Section 8 subsidies available throughout the country, but often having long waiting lists;
* "bridge" subsidies through state, regional or county offices responsible for people with developmental disabilities, commonly used for people waiting for and/or ineligible for Section 8;
* housing subsidies determined on an individual needs basis in conjunction with the provision of home and community-based Medicaid waiver services.

Each of these are subsidies given to individuals as opposed to organizations or other entities. An individual subsidy allows for greater choices by people with disabilities and their families in location and type of housing, makes it affordable for people to live in decent homes, and provides people with disabilities access to typical community housing options. While there are some concerns about the use of disability-specific housing subsidies on a long-term basis, they provide a viable short-term strategy.

I. ORGANIZATIONS: HOUSING SUBSIDIES

State of Connecticut
Department of Mental Retardation
Housing Subsidy Program
90 Pitkin Street
East Hartford, CT 06108
203-528-7141
Contact: Terry Cote, Director of Program Management

This housing subsidy program assists people with mental retardation to meet housing costs attributable to acquiring and using a personal home in the community. The subsidy is available to any person who is eligible for residential services provided by the Department of Mental Retardation, who meets the Department's income guidelines and who has pursued all other funding sources including Housing and Urban Development and Section 8 housing subsidies. The subsidy can be used for the following items:

- rent (including payments for mutual housing and limited equity cooperatives which means residents are also part owners of the development buying shares of the whole rather than just their unit)
- security deposits
- utility costs
- personal property insurance
- costs related to routine maintenance

Residences must meet the same standards as typical Section 8 housing and the subsidy amount is equivalent to that available to a person on Section 8 (i.e., the monthly subsidy pays approximately 70% of a person's monthly housing costs). The program provides information on locating a home, through the use of real estate agents, rental agencies, newspapers, and flyers.

Central Virginia Community Services
Division of Mental Retardation Services
2235 Landover Place
P.O. Box 2497
Lynchburg, VA 24501
804-847-8065
Contact: Ron Dozier, Mental Retardation Services Director

This county community services board in Central Virginia has created a pilot program entitled "the bridge program" in which the State Division of Mental Retardation works closely with the local housing authority in expanding housing subsidy opportunities for people with mental retardation. The Mental Retardation Services Division (MRSD) has devised a way to fund individuals identical to the supports provided by Section 8. In essence, MSRD acts as a "bridge" providing financial support until actual Section 8 funds become available, which can take up to three years. Houses are found by the local housing authority with the same landlords used in Section 8 programs. In this way, transfer to the Section 8 program is easier. Two people are presently funded by the program with up to nine expected to use the program by the summer of 1989.

North Dakota Department of Developmental Disabilities
State Capitol
Bismarck, ND 58505
701-224-2768
Contact: Russ Pittsley

In conjunction with the process of implementing their home and community-based Medicaid waiver, the North Dakota Department of Developmental Disabilities will subsidize housing costs, when necessary, for a person with developmental disabilities to live in a home or apartment either alone or with up to two other people with developmental disabilities. This state supplemental payment is unique in

that each person's situation is reviewed individually and this review takes into account the person's financial status, the specific home in which the person will live, the shared expenses of roommates (if any), and the programmatic determination of whether the state will supplement the costs for an individual to reside alone.

II. RESOURCE MATERIALS: HOUSING SUBSIDIES

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TITLE: Community living for adults in North Dakota: A case study of an apartment program

AUTHOR: Racino, J. A.

PUBLICATION INFORMATION: 1989

Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

COST: $2.85

This qualitative research report includes a description of the use of North Dakota's home and community-based Medicaid waiver, together with the housing supplement, to support adults with developmental disabilities to live in places they lease or own.

HOUSING ASSOCIATIONS AND COOPERATIVES

Individuals involved directly or indirectly in human services are joining with other community members to develop or influence housing associations to include people with disabilities. Housing associations are organizations which finance and provide assistance on housing, may develop long term management support services to cooperatives, and create long-term stability of housing options. Housing associations use a variety of strategies to increase the availability of low and moderate income housing. They make homes available to people who ordinarily could not obtain them through conventional channels.

Cooperatives are defined as housing collectively owned and operated by and for the mutual benefit of people who live there. Cooperatives may be formed or supported by a housing association. While generic cooperatives that include people with disabilities are a recent phenomenon in the United States, Canadian cooperatives have more experience in this area. Generic cooperatives are one means of developing additional community housing that can include people with disabilities.

Human service organizations in the United States are just beginning to recognize the potential for integration through collaboration with housing organizations. In particular, development of housing through associations (instead of facility development by agencies) enables people with disabilities to continue to live in their home even if their relationship with the service providing agency changes.

I. ORGANIZATIONS: HOUSING ASSOCIATIONS AND COOPERATIVES

Perry Housing Association
Box 78
Shawnee, OH 43782
614-394-2852
Contact: John Winnenberg

This housing association, serving Perry County, Ohio, attempts to make homes available to people who cannot ordinarily afford to rent or own homes. The association seeks no-interest or low-interest loans and purchases homes that can be rented or sold to people who cannot obtain homes through conventional means. The housing association has recently been formed and involves approximately 15 people from all walks of life. It will be run by its members who are either looking for or purchasing homes through the assistance of the organization. The association works with Residential, Inc., a residential support service agency, in order to provide opportunities for people with disabilities to secure housing outside of the human service system.

Area Agency for Developmental Services
Region VI
Suite 22, Harris Pond
32 Daniel Webster Highway
Merrimack, NH 03054
603-882-6333
Contact: Beth Raymond, Community Resource Developer

Monadnock Developmental Services, Inc.
106 Roxbury Street
Keene, NH 03431
603-352-1304
Contact: David Johnson, Acting Director

These are two of the area agencies in New Hampshire that are pursuing cooperatives as one of the housing options for people with developmental disabilities

in the state. Each area agency is responsible for the provision of support services to people living in a variety of housing options, including the cooperatives. In the future, Region VI plans to begin with home ownership and family initiated housing programs.

The National Association of Housing Cooperatives
1614 King Street
Alexandria, VA 22314
703-549-5201

This is a non-profit national federation of housing coops, including professional organizations and individuals. The purpose of the organization is to promote the interests of cooperative housing communities. The association produces a bi-monthly newsletter as well as an annual journal. It also offers training workshops which provide technical assistance on how to develop a cooperative. A variety of materials and information on cooperative housing and its development are available for a nominal fee.

Prairie Housing Cooperative
102-113 Market Avenue
Winnipeg, Manitoba, Canada R3B 0P5
204-943-3392
Contact: Rudy Braun

Prairie Housing Cooperative is a non-profit housing association which is operated by people with disabilities and non-disabled individuals throughout Winnipeg. The cooperative has established several "clusters" of houses in which non-disabled neighbors and housemates offer practical support to members with disabilities. Some in-home paid supports are also provided through other agencies. Funding for the cooperative comes from housing subsidies provided through the Canada Mortgage and

Housing Corporation (equivalent to Housing and Urban Development in the United States). This particular cooperative was established in 1982 in Winnipeg and by 1986 had included 20 households or 60 people, twelve of whom have disabilities. More details about this cooperative and its relationship to L'Avenir, a separate cooperative providing supports to people with disabilities, are included in the resource article **People caring about people** described at the end of this section.

The Reservoir Cooperative
Madison Mutual Housing Association
200 North Blount Street
Madison, WI 53703
608-255-6642
(Excerpted from information produced by the Housing and Technical Assistance Project)

This non-profit venture was developed by groups representing people with disabilities and a housing developer. Residents of the cooperative are also part owners of the development. The cooperative apartment complex was designed to meet the needs of different types of people and the concept was conceived with the goal of creating an integrated and multi-generational living environment.

Financing for the project included local community development agencies throughout the City of Madison, tax-exempt bond financing, and funds from the Madison Mutual Housing Association. Through support from Options in Community Living, a private, non-profit residential support agency, people with disabilities receive necessary services in their homes.

Since residents are members of the cooperative but do not solely own the units, they can still use housing assistance payments such as Section 8 certificates.

II. RESOURCE MATERIALS: HOUSING ASSOCIATIONS AND COOPERATIVES

TITLE: Introduction to cooperative housing

AUTHOR: Page, S.

PUBLICATION INFORMATION:

The Cooperative Initiatives Project
Page Associates
236 Gulf Road
Belchertown, MA 01007
413-253-3118
203-523-0890

COST: There will be a minor charge for postage and copying.

This article is a brief and easy introduction to understanding cooperative housing in the United States in which the advantages and elements of coop involvement are discussed. The article points out the potential that coop members have to build a strong sense of community and support. In contrast to individual home owners, coop members are provided with many security and equity benefits. While functioning as a business corporation, coops are operated for the benefit of owner and resident. Each owner has voting privileges. The whole concept of the coop is based on involvement of the members. Though there is an elected board to manage day-to-day operations, membership involvement is highly encouraged and training programs are offered to members regularly.

The reader is provided a range of information about ways to establish cooperative housing, such as constructing new buildings, rehabilitating and purchasing existing structures, or leasing a building and having the cooperative manage that

building. Examples of both coops and funding possibilities in places such as Connecticut, Massachusetts and Wisconsin offer the reader some concrete examples of how such projects have managed to find success.

Also addressed is the creation of mutual housing associations, which ensure that the return on capital investment of original projects is used to develop future housing options and provide long-term stability. This is another avenue that has been taken by groups of people, organizations and governmental bodies interested in housing development for low and moderate income people or to develop long term management support services to several independent coops. This article clarifies basic questions about establishing cooperatives as well as pointing out their many benefits.

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The Prairie Housing Cooperative has restricted itself to providing housing and supports for members with mental handicaps. Since all coops in Canada have a designated purpose (i.e., low income, young families), housing is separated from paid services to insure the service relationship does not affect the security of the person's housing.

The cooperative was developed in response to one man's need to leave the institution. A group of people got together and arranged for housing and support for him, which over time resulted in the cooperative. Funding was procured from the Canadian Housing and Mortgages Corporation (CHMC) through its social housing program (which subsidizes mortgages for coop homes by providing low interest loans). The Manitoba Department of Cooperative Development helped establish the structure of the cooperative and the regional office of CHMC helped purchase the first 18 units.

TITLE: Financing strategies for cooperatives

AUTHOR: Randolph, F., Laux, B., & Carling, P.

PUBLICATION INFORMATION: 1987

In F. Randolph, B. Laux, & P. Carling, **In search of housing: Creative approaches to financing**.

Center for Community Change Through
Housing and Support
University of Vermont
John Dewey Hall
Burlington, VT 05405
802-656-0000

COST: $15.00

This chapter explains how housing coops are developed under corporate laws of a state rather than real estate laws. In order to establish such a corporate body,

articles of incorporation, by-laws, and occupancy agreements must be filed.

Tenant members collectively own and manage the cooperative. The article points out that the nature of a cooperative requires collective decision making and offers natural opportunities for interaction, integration and acceptance. The aspect of permanency is also a factor offering opportunities for joint ownership, decision making and operation.

The chapter explains the financing options that are available for housing cooperatives such as: Housing and Urban Development (HUD) which provides federal mortgage insurance under Section 213 and Farmers' Home Administration (FmHA) which provides cooperative construction and mortgage loans under rural cooperative housing programs. State agencies can be a source of funding if they choose to re-program capital funds which in the past were used to build community facilities or renovate institutions.

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disadvantages of this model, the paper provides information on different structures for cooperatives and alternative financing sources for cooperatives, including mortgage insurance, national cooperative boards, the Federal National Mortgage Association (FNMA) secondary market for cooperative blanket and share loans, state and local government agencies, tax exempt bonds, home ownership assistance programs, equity financing, low income tax credits, foundation and religious organizations, local initiative support corporation (LISC) and enterprise foundations.

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TITLE: Community sponsorship of housing cooperatives

AUTHOR: Wilcox, R.

PUBLICATION INFORMATION: 1987

National Association of Housing Cooperatives
1614 King Street
Alexandria, VA 22314
703-549-5201

COST: $5.00

This booklet discusses advantages and disadvantages of housing cooperatives, what community sponsors can expect from a cooperative, types of housing cooperatives in the United States, and information on how to start a cooperative. The booklet also discusses mutual housing associations (MHA) which are not used extensively in the United States, but may be in the future.

A MHA is housing produced, owned and operated by a not-for-profit, public interest organization where those who develop the housing and those who will live in it join together in membership. The MHA is the umbrella organization that then can sponsor single and multifamily non-profit cooperatives, condominiums and rental housing. The booklet is brief and offers a good overview of some basic questions related to housing cooperatives.

TITLE: Cooperative housing: People helping each other

AUTHOR: Cooperative Housing Foundation and National Association of Housing Cooperatives

PUBLICATION INFORMATION:

Cooperative Housing Foundation
2501 M Street, N.W., Suite 450
Washington, DC 20039

National Association of Housing Cooperatives
1612 King Street
Alexandria, VA 22314

Cooperative housing is a short book offering the reader basic information on housing cooperatives including a brief history of their development, information on who might be interested in living in a coop, how a coop is structured and how to get started. The finances of coop establishment are presented including members' costs and issues in start-up. Finally, the book offers a comparison of rental, individual ownership and cooperative living, including such areas as ownership, community control, management, and tax benefits.

ORGANIZATIONS/RESOURCES CONCERNED WITH HOUSING OPTIONS

This section is an introduction to the veritable wealth of information available on housing. It includes two major types of organizations and resources: (a) those that specifically focus on community living for people with disabilities and which have an interest in promoting integrated housing options, and (b) those that focus on low and moderate income housing issues and may or may not have specific interest in people with disabilities.

The purpose of this section is threefold: to expose people in the disability field to information on integrated housing options and financing, to increase exchange among organizations in different fields working on housing issues, and to increase the awareness of housing organizations of the need to include people with disabilities in their efforts.

While we have reservations regarding equating housing for people with disabilities with low and moderate income housing strategies, the national movement on the promotion of affordable housing needs to be more inclusive of people with disabilities. In addition, the important movement toward home ownership by parents and people with disabilities must be accompanied by new strategies to support people in their own homes and a recognition of the distinction between the choice of parents and the choice of their children.

I. ORGANIZATIONS

Creative Management Associates
P.O. Box 5488
Portsmouth, NH 03801
603-436-6308
Contact: Bob Laux
Cynthia Moran

Creative Management Associates provides consultation and written information regarding financing opportunities that make it possible to pursue alternative housing for people with disabilities. Consultations are provided on housing options such as single family dwellings, integrated apartment programs, cooperatives and condominiums specifically for low income individuals and their families. There is a focus on using a variety of financing strategies, similar to those used by realtors, including the low income tax credit offered through the Tax Reform Act of 1986.

Center for Community Change
Through Housing and Support
University of Vermont
John Dewey Hall
Burlington, VT 05405
802-656-0000
Contact: Paul Carling, Director

This center, based at the University of Vermont, is a national research and training organization focused on housing and community supports for individuals with psychiatric needs. The center provides a publications list that can be ordered for a minimal fee. The publications offer information and resources pertinent to all disability groups in relation to housing issues.

Research and Training Center
on Community Integration
Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340
315-443-3851
Contact: Steven J. Taylor, Director

The Center on Human Policy (CHP) is a national center conducting research and providing technical assistance, training and information on supporting people with the most severe developmental disabilities in the community. As part of its work on individualized supports for adults, the CHP is examining a variety of service characteristics of this approach, including home ownership by people with disabilities, the separation of housing and support components, individualized and flexible supports, ties between individual assessment, planning and funding, and control by people with disabilities of housing and services.

Research and Training Center
on Community Living
University of Minnesota
University Affiliated Programs
Six Pattee Hall
150 Pillsbury Drive, S.E.
Minneapolis, MN 55455
612-624-4848
Contact: Robert Bruininks

This national center carries out research and training activities essential to integrated community living for people with developmental disabilities. Areas of concentration include: a longitudinal study on individuals with severe disabilities entering community facilities, social relationships and networks, recreation and leisure time use, communication, program financing ranging from state level funding to individualized consumer-owned housing, and studies on community living personnel.

Housing Technical Assistance Project (HTAP)
Association for Retarded Citizens
1522 K Street, N.W., Suite 516
Washington, DC 20005
202-785-3388
Contact: Bill Mitchell

This national disability organization is involved with issues in the area of housing for people with disabilities. As a member of the housing committee of the Consortium for Citizens with Disabilities (CCD), a national coalition of the major organizations in this country concerned with the well-being of people with disabilities, the HTAP has information on a variety of issues affecting housing for people with disabilities, such as the National Affordable Housing Act and revisions in HUD 202. This organization, which traditionally has been involved in residential services for people with developmental disabilities, is increasingly interested in promoting small, integrated housing options. The Housing and Technical Assistance Project has been a major effort of ARC-US in the housing area.

McAuley Institute
1320 Fenwick Lane, Suite 600
Silver Spring, MD 20910
301-588-8110

This non-profit corporation assists local efforts to improve and develop permanent low and moderate income housing. It provides technical and financial assistance in developing community-based housing.

As part of their technical assistance program, the Institute helps with project planning for housing development, building networks of housing advocates, assisting in

project review, and developing management programs for low-income housing projects. The Institute also has a revolving loan fund from which it lends money for the acquisition and/or construction of low cost housing.

Available also at the Institute is a databank of over 2,000 organizations that are involved in providing housing for people with low income. The databank includes information on publications, funding sources, case studies, coalitions, and proven techniques.

Institute for Community Economics
151 Montague City Road
Greenfield, MA 01301
413-774-7956

The Institute for Community Economics provides technical assistance, training, and financing to community based non-profit organizations on housing and job needs. Specifically, in the area of housing, it supports organizations such as community land trusts and limited equity housing cooperatives which produce low cost housing and preserve long term affordability. The Institute also operates a revolving loan fund capitalized by loans from socially concerned investors. A series of publications related to community investments, community land trusts, and loan funds are available.

Women's Institute for Housing
and Economic Development
179 South Street
Boston, MA 02111
617-423-2296

This non-profit organization provides housing and economic development expertise in regard to women who head families, have limited resources, and live in substandard conditions. It offers technical assistance, information and education to community groups who serve low income women and their families. The Institute assists community groups to initiate programs in housing, identify and access financing and other resources, and acquire property.

Habitat for Humanity
Habitat and Church Streets
Americus, GA 31709
912-924-6935
(There are also regional offices throughout the U.S.)

Habitat for Humanity is an ecumenical Christian housing ministry that has worked internationally to build a sense of community by having people of all financial means work together to create decent housing. Projects are developed on a local level and are determined on the basis of need, family size and ability to re-pay loans as well as a willingness to volunteer time on a particular project.

Habitat has recently written a statement of purpose for people with disabilities and plans to develop funds which would provide loans and grants to projects for families with members with disabilities. The group has also been involved in creating some barrier free environments.

Local Initiative Support Corporation (LISC)
666 Third Avenue
New York, NY 10017
212-949-8560

This non-profit organization channels private sector funds to non-profit community based development corporations (CDCs). LISC acts as part funder and project broker to help the CDCs work with banks and local governments to build decent low-income housing. In each area or community in which they are involved, corporations and foundations contribute funds that are matched by the national LISC. LISC seldom finances more than 20% of any one project, but often its involvement encourages further involvements by other local investors and government. LISC also looks at creative ways to adapt high finance instruments for use by CDCs.

Enterprise Foundation
505 American City Building
Columbia, MD 21044
301-964-1230

This non-profit organization works through a national network of non-profit neighborhood and community organizations to assist people with low incomes to help themselves in obtaining affordable housing and jobs.

The Enterprise network consists of 100 local non-profit housing groups and maintains a strong focus on neighborhood and grassroots groups working together to build stronger communities. Written material providing more specific information on what has been done in cities throughout the country is available upon request.

National Low Income Housing Coalition (NLIHC)
1012 14th Street, N.W., #1500
Washington, DC 20005
202-662-1530

This broad-based coalition is developing a growing number of state-based low income housing coalitions whose job it is to educate, advocate, and organize for the creation of decent affordable housing for people with low incomes.

NLIHC is also associated with the Low Income Housing Information Service, a non-profit educational organization which publishes a monthly newsletter and has provided some special projects such as networking, technical assistance support and resource information.

The organization also offers a publications list including technical assistance manuals on mutual housing associations, research and policy papers looking at low income housing needs, and papers on selected legislation and congressional testimony related to low income housing.

II. RESOURCE MATERIALS

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Volume II, **The financing mechanisms**, offers detailed summaries of major financing mechanisms on the federal, state and private levels that can be used to develop affordable housing for people with disabilities. Programs offered through HUD, and state initiatives such as housing trust funds and mortgage insurance, are described along with where information on each can be obtained.

The project has also produced small individual packets on organizations in different states that have used these methods to provide affordable and integrated housing for people with disabilities.

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TITLE: In search of housing: Creative approaches to financing integrated housing

AUTHOR: Randolph, F., Laux, R., & Carling, P.

PUBLICATION INFORMATION:

Center for Community Change Through
Housing and Support
University of Vermont
John Dewey Hall
Burlington, VT 05405
802-656-0000

COST: $15.00

This monograph outlines and identifies effective resources in relation to housing opportunities for people with labels of mental illness. It highlights the economics of housing, offers more specific insight into understanding real estate language, and discusses private investor ownership and financing strategies for consumer and family ownership. An overview of government programs which finance housing on a federal, state and local level is included. Finally, it addresses issues of implementation of integrated housing offering a six step process of what should be looked at in such a pursuit. The reader is provided with a list of references and a bibliography. Though the text focuses on the mental health system, it offers a great deal of useful information applicable for people and agencies desiring to understand integrated housing for other individuals.

TITLE: What should I know about residential services

AUTHOR: Turnbull, R. H., Turnbull, A. P., Bronicki G. J., Summers, J. A., & Gordon-Roeder, C.

PUBLICATION INFORMATION: 1989

In Turnbull, R. H., Turnbull, A. P., Bronicki G. J., Summers, J. A., & Gordon-Roeder, C. (1989). **Disability and the family: A guide to decisions for adulthood**. Baltimore, MD: Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

COST: $29.00

This chapter is included here because it is written specifically for families and includes a section on consumer and family home ownership. It discusses types of creative financing that can be used, and emphasizes the importance of careful and detailed planning. It also offers a case example of how one family created the ability for their son to own his own home.

TITLE: Shelterforce

AUTHOR: National Housing Institute

PUBLICATION INFORMATION:

National Housing Institute
439 Main
Orange, NJ 07050

COST: $15.00/year

This is a bi-monthly publication of the National Housing Institute which serves a network of housing advocates and professionals with information about affordable housing strategies, industry issues, and workshops and events taking place in the area of housing. Other purposes of the publication are to build a national network of tenant and housing groups, to provide resources and information on the creation and

preservation of decent, affordable housing for all, and to promote neighborhood development in the promotion of housing options.

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TITLE: New housing policy for America: Recapturing the American dream

AUTHOR: Schwartz, D. C., Ferlauto, R. C., & Hoffman, D. N.

PUBLICATION INFORMATION: 1988

Temple University Press
Philadelphia, PA

This book examines what the 1980s has brought to the area of housing in terms of a decline in home ownership, increase in homelessness and decrease in affordable and available rental units, and discusses what challenges will be faced in the 1990s.

In the 1990s, most analysts agree that at least four demographic trends are likely to pose challenges to housing policies: (1) the huge increase in the number of people 75 years and older; (2) the sharp upturn in the number of single people living alone and single parent female headed households; (3) the increase in young families in early years of home buying; and (4) the larger concentration of poor families.

The number of very low income Americans is expected to increase by almost 6 million by the 1990s and experts fear that, by the year 2000, one third of all Americans and 70% of the poor will confront inadequate and unaffordable housing. The book discusses state programs in the 1980s which must be considered in national housing policy yet these alone cannot meet the housing needs that exist and will continue to arise.

The book offers a good overview of the housing issues related to policies, but is not creative in generating solutions for the elderly and people with disabilities. It includes a variety of options presently being used such as group homes. They do talk, however, about shared housing and staying with family and friends and look at some programs as being untapped (e.g., ECHO, a model from Australia which has small houses around a central area). It offers a very good overview of the housing situation in America today.

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GLOSSARY

Community based development corporation is a local organization or group which shares a common goal to work together in building and developing stronger communities.

Community development entails a variety of activities done within or on behalf of a community to add to or enhance it in some way. It may include housing construction, developing cooperatives or rehabilitation of structures.

Community land trusts are private, non-profit organizations which acquire and hold land for the benefit of the community. They provide secure and affordable access to land and potential housing for community residents.

Cooperative housing is joint corporate ownership of a housing development by those who reside on the premises. There are two types of cooperatives, market coops where units are bought and sold at market prices, and limited equity cooperatives where housing affordability is maintained over the long term.

Dedicated sources of revenue are sources of capital obtained through interest generated by investments, development fees, or surtax in a particular fund (i.e., housing trust fund or another trust fund). This capital is then dedicated for the use of that particular group.

Enterprise foundation is a non-profit organization working with neighborhoods and community organizations to help low income people obtain affordable housing and jobs.

Equity is the interest or value that an owner has in his or her property over and above any mortgage indebtedness.

Farmers' Home Administration (FmHA) provides housing loans to low to moderate income families in rural areas. Loans are particularly used for construction, repair, purchase of housing, adequate sewage disposal, purchase or installation of essential equipment, or to purchase a site to place a dwelling.

Federal mortgage insurance Section 213 ("Cooperative Housing Insurance") is a program available to non-profit cooperative housing organizations or trusts that construct homes for members of trust beneficiaries.

Housing and Urban Development (HUD) Section 202 is currently the major source of financing for the development of rental housing for low and moderate income people with disabilities.

Local initiative support corporation is a non-profit organization that acts as a funder and broker to assist community based development corporations in working with local governments and banks to build low cost housing.

Mortgage insurance is a program offered through HUD and administered by the Federal Housing Association (FHA), a branch of HUD, which insures approved FHA lenders against loss on mortgages placed by them. Mortgage insurance does not provide direct loan funds but insures loans made by financial institutions.

Mutual housing association is an organization interested in developing and preserving housing stock over the long-term. It builds a body of expertise in mutual housing or coop development and provide a range of support services.

Section 8 housing vouchers is a HUD program which provides low income families with a choice in renting units beyond existing fair market rents through rent subsidies. Eligibility is given to people occupying substandard housing or paying more than half of their income for rent.

Tax exempt bond financing entitles cooperative ownerships structured as charitable organizations to be eligible for public purpose bond financing. Tax exempt bond programs allow "share" loans for cooperative purchases.

Trusts are written instruments that give title to or an interest in real estate. A trustee holds title on behalf of the lender, known as the beneficiary who is the legal owner.

This glossary has been adapted from materials produced by the following:

Randolph, P. H., Laux, B., & Carling, P. J. (1987). In search of housing. Burlington, VT: The Center for Community Change Through Housing and Support, University of Vermont.

Housing Technical Assistance Project (HTAP)
Association for Retarded Citizens
1522 K Street, N.W., Suite 516
Washington, DC 20005

Institute for Community Economics
151 Montague City Road
Greenfield, MA 01301